

Photocopy and Use Authorization

In presenting this thesis in partial fulfillment of the requirements for an advanced degree at Idaho State University, I agree that the Library shall make it freely available for inspection. I further state that permission for extensive copying of my thesis for scholarly purposes may be granted by the Dean of the Graduate School, Dean of my academic division, or by the University Librarian. It is understood that any copying or publication of this thesis for financial gain shall not be allowed without my written permission.

Signature_____

Date_____

Factors Contributing to Caregiver Satisfaction with Autism Spectrum Disorder Evaluation
Feedback

by

Karolina Štětinová

A dissertation

submitted in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy in the Department of Psychology

Idaho State University

Summer 2022

To the Graduate Faculty:

The members of the committee appointed to examine the dissertation of KAROLINA ŠTĚTINOVÁ find it satisfactory and recommend that it be accepted.

Robert Rieske, PhD
Major Advisor

Samuel Peer, PhD
Committee Member

Xiaomeng Xu, PhD
Committee Member

Joel Bocanegra, PhD
Committee Member

Elizabeth Fore, PhD
Graduate Faculty Representative

Acknowledgments

This study could not have been completed without the guidance of my graduate advisor Dr. Rieske, who always inspired my pursuit of becoming a great scientist, clinician, and overall, a good human being. I would also like to acknowledge my committee members, who were willing to share their expertise (even during the summer break) to help me develop a meaningful research study.

Furthermore, I would never be able to make it this far as an international student in the United States without the emotional and financial support of my lovely family and my brilliant partner. Thank you for always standing behind me but also challenging me to strive for more.

Lastly, I would like to recognize all individuals living with autism spectrum disorder, their families, and the providers that care for them. The data collection would not be possible without the caregivers who took their time to reflect on their experiences. My hope is that this study could, one day, benefit the autism community and their professional allies.

April 26, 2021

Robert Rieske
Psychology
MS 8112

RE: Study Number IRB-FY2021-110: Factors affecting caregiver experiences with the autism spectrum disorder diagnostic process

Dear Dr. Rieske:

Thank you for your responses to a previous review of the study listed above. I agree that this study qualifies as exempt from review under the following guideline: Category 2.(i). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording).

The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects.

This letter is your approval, please, keep this document in a safe place.

Notify the HSC of any adverse events. Serious, unexpected adverse events must be reported in writing within 10 business days.

You are granted permission to conduct your study effective immediately. The study is not subject to renewal.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Tom Bailey (208-282-2179; fax 208-282-4723; email: humsubj@isu.edu) if you have any questions or require further information.

Sincerely,

Ralph Baergen, PhD, MPH, CIP
Human Subjects Chair

TABLE OF CONTENTS

List of Tables	vii
Abstract	viii
Introduction.....	1
ASD Classification and Diagnostic Criteria	2
Diagnostic Process of ASD.....	3
Assessment	3
Feedback.....	9
Current Study	21
Hypotheses	22
Methods.....	23
Participants	23
Materials.....	27
Procedure.....	29
Data Analyses.....	30
Results.....	32
Assumptions	32
Predicted Covariates.....	33
Multiple Regression Model.....	34
Non-Parametric Correlations	38
Additional Analyses	40
Discussion	45
Implications and Limitations	52

References	55
Appendix 1	68

List of Tables

Table 1 List of Hypotheses	22
Table 2 Caregiver Demographic Information.....	25
Table 3 Child Demographic Information.....	26
Table 4 Additional Family Characteristics	27
Table 5 Descriptive Statistics – All Continuous Variables Before Transformation	33
Table 6 Predicted Covariate Variables and Feedback Satisfaction	34
Table 7 Multiple Regression Results for Feedback Satisfaction	37
Table 8 Partial and Semi-Partial Correlation Coefficients	37
Table 9 Spearman’s (ρ) Correlation.....	39
Table 10 Partial Correlation Coefficients	39
Table 11 Feedback Session Descriptives	40
Table 12 Feedback Session Process.....	42
Table 13 Provider Characteristics.....	43
Table 14 Caregiver Emotions During Feedback.....	44

Factors Contributing to Caregiver Satisfaction with Autism Spectrum Disorder Evaluation Feedback

Dissertation Abstract – Idaho State University (2022)

The current study investigated caregiver experiences with autism spectrum disorder (ASD) feedback process and factors contributing to caregiver satisfaction. Past literature suggested that caregivers often feel distressed during ASD feedback and report dissatisfaction with the information provided during the session. For this reason, the current study aimed to evaluate whether factors such as family demographics, diagnostic processes, provider characteristics, and/or level of emotional distress are associated with caregiver satisfaction with ASD feedback. Caregivers of children previously diagnosed with ASD had the opportunity to participate in the study through an online survey. The results of multiple regression indicated that two predictor variables (i.e., waitlist length and an emotional distress count) were negatively associated with caregiver feedback satisfaction, while two predictors (i.e., provider advocacy and the value of caregiver input) showed a positive relationship with the outcome variable. Due to significant gaps in the extant literature examining the process of ASD evaluation, the study further reported on details such as the session length and elements included in the feedback process, intending to elucidate common feedback practices across providers in the United States. Considering the current findings, future research should focus on comparing different perspectives (e.g., caregiver, provider, child) and evaluating how caregiver preparedness for the child's ASD diagnosis relates to feedback satisfaction.

Key Words: ASD, autism, evaluation feedback, caregiver satisfaction

Introduction

It is estimated that one in 54 children is diagnosed with autism spectrum disorder (ASD) in the United States (Maenner et al., 2020). In recent years, the call for early identification of ASD has also increased as intensive early intervention programs became strongly linked to better client outcomes (Perry et al., 2011; Woods & Wetherby, 2003). Caregivers thus play a crucial role in facilitating children's access to timely diagnostic and treatment services. Unfortunately, evidence suggests that caregivers often face challenges while completing the ASD evaluation process with their children (Smith-Young et al., 2020).

Many caregivers report difficulty finding providers when seeking an ASD evaluation, experiencing diagnostic delays of 3.5 years on average (Crane et al., 2015; McKenzie et al., 2015), which can be exacerbated further by certain sociodemographic factors such as racial/ethnic minority and socioeconomic status (Hidalgo et al., 2015; Martinez et al., 2018). Aside from the difficulty accessing professional diagnostic services, caregivers report concerns associated with the length and cost of the evaluation, the quality and depth of provided information, and the overall level of the received care and support (Crane et al., 2015). It is also worth mentioning that providers themselves frequently report a lack of formal training in ASD diagnostic processes, and, in practice, there appears to be great variability in professional approaches to ASD evaluation (Aiello et al., 2017; Allen et al., 2008; Skellern et al., 2005; Ward et al., 2016).

Considering the above-mentioned factors, it is not surprising that caregivers generally report low satisfaction with the ASD diagnostic process (Howlin & Moore, 1997; Mansell & Morris, 2004). There is, therefore, a considerable need for improvements in the standardization and delivery of ASD evaluation services that are informed by caregivers' needs. However, the

extant research on this topic primarily focuses on the assessment process, and only a handful of studies are dedicated to the process of ASD diagnosis delivery during a feedback session.

ASD Classification and Diagnostic Criteria

Even though the term “autism” has been around since the 1940s when Leo Kanner used it to describe children with impairments in social interaction (Kanner, 1943), the diagnosis of autism was first formally established in 1980 by the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III; American Psychiatric Association [APA], 1980). Nonetheless, it was not until the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2013) that this diagnosis underwent major revision and re-conceptualization.

Due to the similarities in symptomatology and low diagnostic utility, the DSM-5 newly combined several previously established diagnoses including autistic disorder, Asperger’s syndrome, and pervasive developmental disorder (PDD) into one diagnosis: autism spectrum disorder (ASD; Evans, 2013). Another novelty is the dimensional approach that the DSM-5 utilizes when describing the symptoms of ASD, requiring both the presence of “persistent deficits in social communication and social interaction across multiple contexts” as well as the presence of “restricted, repetitive patterns of behavior, interests, or activities” (APA, 2013, p. 50-51). The manual provides an illustrative list of diagnostic symptoms in each category, including low social-emotional reciprocity; reduced sharing of interests, emotions, or affect; abnormalities in eye contact and body language; difficulties in sharing imaginative play or in making friends; lining up toys; echolalia; and unusual interest in sensory aspects (APA, 2013). Any of the listed symptoms may be present at the time of evaluation or by history, and their onset must be traceable to the early developmental period. Moreover, they must cause clinically significant

impairment in important areas of daily functioning, and the symptoms should not be better explained by intellectual disability (ID) or global developmental delay (GDD) alone. According to the DSM-5, when providing ASD diagnosis, providers should also identify the severity level and provide specifiers that assist in describing individual differences in symptoms presentation. These specifiers outline whether the diagnosis is associated with intellectual impairment, language impairment, and/or established medical, genetic, environmental, or behavioral conditions (APA, 2013). Notably, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR; APA 2022) preserved the classification of ASD as described above, with minor changes in wording to clarify the inclusion of all of the mentioned symptoms under the criterion A and one of the specifiers indicated that the ASD diagnosis is “associated with another neurodevelopmental, mental, or behavioral problem.”

Diagnostic Process of ASD

Considering the dimensionality and breadth of ASD, it is clear that this diagnosis calls for a comprehensive evaluation of an individual’s needs, strengths, and weaknesses across multiple areas of functioning. Only by engaging in a comprehensive evaluation process that utilizes evidence-based assessment tools, can providers capture the individual differences in the presentation of ASD symptoms and provide their clients with useful recommendations (Ozonoff & Goldstein, 2018). However, the question then arises: “How should such a process look like to be effective and benefit the client?”

Assessment

Within the United States, there is currently no unitary consensus regarding the process of ASD evaluation. Nonetheless, the American Academy of Pediatrics (AAP; Hyman et al., 2020) recently developed a clinical report summarizing recommendations for the identification,

assessment, and management of children with ASD. The authors recommend that all children should be screened for ASD symptoms using standardized autism screening tests during their primary care visits at 18 and 24 months of age (Hyman et al., 2020). The guidelines suggest using the Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al., 2009) when screening children between 12–30 months old, but no recommendations are provided for children older than 30 months due to a lack of validated instruments that would be easily accessible to pediatric practice.

Consistent with Filipek et al. (1999), AAP guidelines further recommend timely referral for diagnostic evaluation and early intervention services following a positive screen. Hyman et al. (2020) state that while school psychologists or general pediatricians may provide the initial diagnosis to facilitate a child's access to services, most cases require the involvement of a specialist (e.g., neurodevelopmental pediatrician, psychologist, neurologist, or psychiatrist) who can conduct a careful review of a child's developmental history and observation of symptoms (Hyman et al., 2020).

AAP guidelines propose that the diagnostic process should consist of an interview with the primary caregivers which can be supplemented with standardized instruments such as the Social Communication Questionnaire (SCQ; Rutter et al., 2003), Social Responsiveness Scale–2 (SRS-2; Constantino & Gruber, 2012), Behavior Assessment System for Children–3 (BASC-3; Reynolds & Kamphaus, 2015), Diagnostic Interview for Social and Communication Disorders (DISCO; Leekam, 2013), Child Behavior Checklist (CBCL; Achenbach, 1999), and Autism Diagnostic Inventory-Revised (ADI-R; Rutter et al., 2003b). For structured observation, AAP guidelines recommend using the Autism Diagnostic Observation Schedule–2 (ADOS-2; Lord et al., 2012) and/or the Childhood Autism Rating Scale–2. (CARS-2; Schopler et al., 2010).

Additionally, the guidelines endorse assessing for co-occurring developmental conditions through evaluation of cognitive, adaptive, language, motor, and sensory functioning, but no specific recommendations for measures that can be used to evaluate these areas are provided (Hyman et al., 2020).

Such ambiguity can be problematic as the inclusion of DSM-5 ASD specifiers deems assessment of intellectual and language functioning essential (APA, 2013), and research has shown that intellectual, language, and adaptive functioning are important predictors of individual outcomes (Bavin et al., 2014; Kanne et al., 2010; Kjellmer et al., 2012; Magiati et al., 2014; Thurm et al., 2015). For these reasons, the inclusion of measures that evaluate these three areas within the core ASD battery should be perceived as necessary rather than optional (Ozonoff et al. 2005; Steiner et al., 2012). In fact, Ozonoff et al. (2005) and Steiner et al. (2012) developed a review of assessment tools available for ASD evaluation that included measures of intellectual, language, and adaptive functioning within the core battery. The articles became an unofficial guiding resource for providers completing the evaluation of autism, which is why Goldstein and Ozonoff (2018) later developed a more updated version of the clinician's guide to ASD assessment.

Taken all together, there appears to be a sufficient amount of literature providing an overview of available, psychometrically sound measures that could be used when assessing ASD and comorbid problems (Goldstein & Ozonoff, 2018; Hyman et al., 2020; Ozonoff et al. 2005; Steiner et al., 2012). However, the research seems to be falling short when providing providers with empirical evidence that could help to prioritize one measure over another, forcing the providers to rely on practical constraints such as length of administration or cost of measures to dictate their choices when developing the core ASD assessment battery (Ozonoff et al., 2005).

Furthermore, aside from noting that the assessment of ASD should be multidisciplinary when possible, the above-discussed articles do not provide additional recommendations regarding the best practice (e.g., session length, setting, timing, and training requirements). It is, therefore, likely that the standards of ASD assessment vary significantly across sites and providers.

Among the few studies that explored variation in provider training and practices during ASD assessment belongs the research of Skellern et al. (2005). In their study, the authors collected information from 79 pediatricians and 26 child psychiatrists located in Queensland, Australia. The findings indicated that pediatricians perceived their level of training for ASD evaluations as significantly worse than child psychiatrists. The perceived adequacy of training was, however, not associated with the length of experience in clinical practice or other provider characteristics such as gender, practice setting, and type of practice. Importantly, there was great variability in the assessment practice among providers, especially concerning reliance on clinical judgment and usage of standardized measures. Specifically, Skellern et al. (2005) found that while 96% of the surveyed providers used informal direct observations, only 19% utilized autism-specific diagnostic assessment tools such as the ADI, ADOS, DISCO, or CARS. When collecting information from others, 99% of providers included parent reports, and 97% included additional reports (e.g., teachers).

Following these findings, Ward et al. (2016) decided to evaluate provider perceptions of the assessment and diagnosis of autism across Australia. The researchers recruited 42 pediatricians, 54 psychologists, and 8 psychiatrists who anonymously reported on their frequency of consultation-seeking, diagnostic method, perceived adequacy of training, and perceived utility of different assessment measures. The findings indicated that 55% of providers reported having a waitlist longer than 1 month, with pediatricians and psychiatrists being

significantly more likely to have client waitlists than psychologists. Interestingly, psychologists were found to take significantly longer time to complete an ASD assessment compared to both pediatricians ($r = .46$) and psychiatrists ($r = .26$). In total, 92.3% of the surveyed providers reported using the “wait and see” approach at some time. Nonetheless, compared to other providers, psychologists were significantly less likely to use this approach ($r = .36 - .41$), and they also reported weaker levels of agreement with the statement that “ASD diagnosis is difficult” ($r = .28 - .32$; Ward et al., 2016). Overall, 79% of the sample reported that they find it difficult to diagnose ASD in a child under the age of 2 years. Also, psychologists were, during the assessment process, more likely to implement standardized interview and observation measures such as the ADI-R and/or ADOS. Compared to pediatricians, psychologists also were more likely to include reports from additional informants (e.g., day-care providers, teachers), and compared to psychiatrists, they were more likely to complete a cognitive assessment with clients. Additionally, pediatricians were less likely to utilize the diagnostic criteria of DSM-IV-TR compared to psychologists and psychiatrists.

Unfortunately, to date, no studies comparing ASD assessment practices among different providers have been completed in the United States. Nonetheless, Allen and colleagues (2008) investigated ASD assessment practices among 117 school psychologists based in Georgia, South Carolina, North Carolina, and Ohio. The average self-reported expertise with ASD assessment was 3.5 on a 5-point scale (i.e., slightly above average). The findings indicated that the school psychologists most commonly utilized CARS, with 54% of providers using this measure 76%–100% of the time. The second most commonly utilized measure was the Gilliam Autism Rating Scale (GARS), with 27% of providers utilizing this measure 76%–100% of the time. Only 18% of providers reported using the ADOS 76%–100% of the time, and 61% of providers reported

that they *never* used this measure for ASD assessment. When looking at additional practices among school psychologists, 80% of providers reported completing cognitive testing, 79% reported completing in-class observation, 75% included developmental questionnaires, 74% included adaptive behaviors scales, 67% completed a developmental interview with caregivers, and 62% of providers administered academic achievement tests 76%–100% of the time. Beyond caregivers, the most commonly included informants were speech/language pathologists, general education teachers, and special education teachers.

Similar results were obtained by Aiello et al. (2017), who surveyed 402 school psychologists nationwide, finding that less than 25% engaged in a comprehensive, evidence-based assessment of ASD that would include assessment of major areas of development as well as ASD-specific measures. The most commonly utilized measures were ASD checklists (e.g., GARS-2). The results also showed that past training on ASD, working with young children with ASD, and geographic location were all associated with greater usage of evidence-based assessment practices (Aiello et al., 2017).

Overall, there appears to be a discrepancy between some of the theoretical recommendations provided by AAP guidelines and Goldstein and Ozonoff (2018) and clinical practice (Aiello et al., 2017; Allen et al., 2008; Skellern et al., 2005; Ward et al., 2016). ASD assessment is a complex process requiring extensive understanding of the diagnostic criteria, human development across numerous areas of functioning, as well as sociocultural and biological factors that can influence symptom presentation (Huerta & Lord, 2012). It is, therefore, likely that in addition to intensive but otherwise general ASD training, providers would benefit from more detailed, evidence-based guidelines that also consider factors such as time and cost.

Feedback

Even though the main goal of a diagnostic process should be to determine appropriate intervention and resources that could benefit the client and lead to an improvement in functioning (Ozonoff & Goldstein, 2018), there appears to be a gap in research investigating how information about the assessment outcomes is or should be translated into treatment recommendations and shared with clients. This is problematic as the results of an assessment, regardless of their validity, can be perceived as useless if the client receiving the feedback does not find them important or interesting (McGrath, 2001). With caregivers, the acceptance of the assessment results can be further threatened by the finding that parents are likely to experience significant distress when their child is provided with diagnoses of cognitive and developmental disabilities (Graungaard & Skov, 2007; Keenan et al., 2010; Whitaker, 2002). Specifically, some parents reported feeling overwhelmed, anxious, and confused after receiving an ASD diagnosis (Whaley, 2007), and others described mixed feelings consisting of relief, devastation, and self-blame (Farrugia, 2009; Midence & O'Neill, 1999; Ooi, et al., 2016). Providers thus play a crucial role in making the feedback a useful and supportive experience for the caregivers as studies have found an association between effective feedback and greater caregiver satisfaction and treatment involvement (Boyd & Corley, 2001; Brogan & Knussen, 2003; Keenan et al., 2010).

Unfortunately, providers often report a lack of formal training in providing this information to families (Merker et al., 2010). For example, Harnett et al. (2009) showed that professionals find it difficult to approach the task of providing the diagnosis to parents in a sensitive manner due to a lack of formal training and support. While both parents and professionals supported the idea of providing the family with realistic but hopeful messages during feedback, only 47% of parents reported actually receiving these messages (Harnett et al.,

2009). A national survey that included data from 329 licensed psychologists also indicated that there is a strong reluctance within the field to break bad news to clients (i.e., the Minimizing Unpleasant Message [MUM] effect; Merker et al. 2010). Participants in this study were significantly more reluctant to break bad news than good news, which was in 30.6% of cases primarily due to anxiety, and only 2.7% of psychologists reported being familiar with existing recommendations about breaking bad news (e.g., providing major diagnosis) to their clients (Merker et al., 2010). Therefore, future directions should focus on the development of evidence-based guidelines and training materials that would allow for improvement in delivery and standardization of the feedback process among providers.

Guidelines & Goals. Due to the current lack of formal AAP or APA guidelines, US providers often rely on recommendations from autism advocacy organizations during ASD feedback delivery. For example, in 2012, a collaboration of Autism Speaks Autism Treatment Network and Autism Intervention Research Network on Physical Health (AIR-P) developed a manual that discusses best practices when delivering feedback to families affected by autism (Austin et al., 2012). The manual defines feedback as a session during which providers meet with the family after the evaluation process to discuss the findings from the assessments, the diagnoses, and the recommendations. Nonetheless, according to the manual, ASD feedback should not be limited to the final session. Instead, providers should be aware that feedback extends throughout the evaluation process, and everything that happens during the course of the evaluation may help to prepare the family for the feedback session. Specifically, providers should inform the caregivers that they are part of the evaluation team and encourage them to ask questions and provide information and observations at any time. The caregivers should also be familiarized with the purpose and process of the evaluation during the initial session, and

providers should refrain from providing vague answers or withholding information from the family even if the diagnostic decision has not yet been fully established. Per this manual, providers should strive to develop warm and supportive relationships with the family and be flexible when tailoring the evaluation to the family's needs.

When preparing for the feedback session, there are several factors that providers should consider. First, previous research suggested that delays in feedback can be associated with family dissatisfaction (Howlin & Moore, 1997), and, therefore, providers should strive to schedule the final session soon after the end of the assessment. Providers are also encouraged to schedule enough time to discuss the results to provide space for questions and in-session processing of the family's thoughts and emotions. Austin et al. (2012) further encourage providers to open the feedback session to other individuals who can provide support for the family but recognize that doing so can lead to changes in the session dynamic. Providers should also be cognizant of the fact that the presence of small children in the feedback session may be disruptive and be willing to discuss the preferences with the family (Austin et al., 2012). Consideration of the clients' cultural background is also important when planning the feedback session as the family's values and beliefs may influence understanding and acceptance of the diagnosis and recommendations. Lastly, according to Austin et al. (2012) providers should pay attention to the physical setting of the feedback session, striving to provide the family with a private, comfortable, and distraction-free environment.

During the actual session, providers should begin by inquiring about changes and/or progress since the last assessment session, acknowledging the family's contributions to the evaluation process, and providing an overview of the feedback session process (Austin et al., 2012). Providers are also encouraged to provide both verbal and written information (e.g., an

assessment report) and focus on the child's strengths and needs when reviewing the results of the assessment. When discussing the diagnosis of ASD and other comorbid diagnoses, the manual recommends that providers use clear and direct language. Providing the family with time to process the meaning of the diagnosis within the session is particularly important as research suggests that receiving an ASD diagnosis can be an overwhelming experience. When explaining the reasons why a client meets the diagnostic criteria for ASD, the providers should be able to provide psychoeducation regarding symptoms and areas of functioning that are impacted (e.g., social communication; Austin et al., 2012).

Lastly, the feedback session should be completed by providing the family with recommendations and next steps. Austin et al. (2012) state that recommendations should be both broad (e.g., behavioral interventions) and specific (e.g., local providers of Applied Behavior Analysis [ABA] therapy), and they may target different areas of the client's functioning including medical, language, behavioral, adaptive, academic/occupational, motor, and safety. In addition, the AAP guidelines also recommend that ASD assessment is followed by etiologic evaluation such as genetic testing (Hyman et al., 2020).

For greater clarity, Austin et al. (2012) suggest organizing recommendations based on immediate importance. Providers should also inform the family about their ability to provide ongoing support or referrals to other professionals who can act as a source of support. The authors recommend ending the session on a positive note by discussing the client's and family's strengths and promoting optimism and hope in the caregivers. It is important to note that the provider's guide is also accompanied by a quality checklist and a series of videos that were designed to provide providers with information and tools to promote productive and positive feedback sessions (Austin et al., 2012). The authors, however, state that the components of the

feedback presented within the manual are not all-inclusive, encouraging providers to tailor the strategies to their and the family's needs and establish a warm relationship with clients.

Overall, Austin et al.'s (2012) guide appears to be a useful and detailed resource that providers can turn to when conducting ASD feedback sessions. However, it is important to note that the literature included within the guide is often not specific to ASD, and it does not account for changes in the conceptualization of ASD within DSM-5 that may have influenced the assessment and feedback process as well as the provider's/family's needs. Therefore, practical questions about the utility and applicability of the provided recommendations arise. Not only that there is a limited amount of research investigating the actual practices during the feedback session, making it unclear whether providers are following the guidelines, but, more importantly, it is unclear whether the recommendations, when implemented, make difference in the family's experience and satisfaction with feedback. An in-depth analysis of caregiver experiences and satisfaction with ASD assessment and feedback process thus should be conducted.

Caregiver Perceptions. One of the earlier studies that investigated this topic was conducted by Quine & Pahl (1986; 1987). The authors examined the reactions of 190 parents after learning that their child has a neurodevelopmental disability. The researchers interviewed the parents using a structured interview, asking several questions about the time the parents were first informed about their child's disability. Parental satisfaction was associated with the age of the child when the diagnosis was first confirmed. The results also showed that parents were dissatisfied with the delays in the diagnostic process, and about two-thirds of parents were also dissatisfied with the information that was provided by the medical professionals. Overall, parents were found to value early acknowledgment of the presence of a problem, honesty about uncertainty, and a sympathetic approach from the side of providers.

Similarly, Nursey et al. (1991) found that parents were more in favor of being given information about their child's handicaps earlier than doctors were and that they saw themselves as the primary decision-makers. Some parents also reported dissatisfaction with the initial evaluation process as they found it difficult to persuade the providers that "something was wrong." However, the results of this study also showed that there were no significant differences between parental and provider perceptions about the fullness of explanations provided during a feedback session and the protection of parents from shock and unpleasant information about the child's mental handicap (Nursey et al., 1991).

One of the largest studies investigating the autism evaluation process and satisfaction collected 1,295 responses from United Kingdom (UK) caregivers (Howlin & Moore, 1997). Based on the findings, parents tended to initially share concerns with their general practitioners (GPs), but in the majority of the sample, these concerns were not properly acknowledged until later stages, resulting in diagnostic delays (i.e., average delays of 3.81 years following the initial visit). When asked about their satisfaction with the process, 49% of caregivers selected "not very" or "not at all" satisfied while 35% reported being "very" or "quite" satisfied (Howlin & Moore, 1997). Almost 35% of participants also reported considerable dissatisfaction with the support from the providers after receiving the diagnosis, with 17% of parents receiving no support or perceiving benefits from the evaluation.

A different approach was utilized by Midence and O'Neill (1999) who conducted a qualitative study investigating parental satisfaction with the autism evaluation process in four UK caregivers. The findings suggested that all of the recruited parents were initially provided incorrect advice or diagnosis (e.g., fragile X syndrome, deafness, eye problems), and one mother reported being blamed for the child's behaviors. Some of the parents reported low support from

their GPs, resulting in a decision to seek help from specialists. According to Midence and O'Neill (1999), after receiving the diagnosis of autism, most parents reported feeling relieved to know what was “wrong with their child,” and only one family reported difficulties accepting the diagnosis. The parents also reported a decrease in their sense of guilt and blame after receiving the diagnosis and highlighted the need for receiving the “label” and learning what to do next (i.e., practical help). All of the participating families reported the hope that their children will be able to live independently in the future (Midence & O'Neill, 1999).

Other, smaller-scale studies investigating parental satisfaction with ASD evaluation and feedback were completed in Scotland, France, and Ireland (Brogan & Knussen, 2003; Chamak et al., 2011; Keenan et al., 2010). Brogan and Knussen (2003) surveyed 126 Scottish parents and found that 55% of participants were satisfied with the disclosure of ASD diagnosis during the feedback. The level of satisfaction was found to be positively correlated with the perceived quality of the shared information and professionals' communication style and manners. Surprisingly, the level of satisfaction with the disclosure was not related to the age of the child or diagnostic delays (Brogan & Knussen, 2003).

Keenan et al. (2010) collected information from 95 caregivers from Ireland about their experiences with forward-planning following autism diagnosis, finding that 49% of the parents did not think that the diagnostic process was completed in a timely and professional manner or that information was presented clearly. Consistently with the above-mentioned findings, 77% of parents felt like the recommendations were insufficient, especially when considering the cost of the evaluation process. Nonetheless, 99% of parents and professionals agreed that increased support and guidance during the diagnostic process is needed, 98% of parents and 92% of professionals believed that parents should be more involved during the development of

recommendations and future plans, and 100% of parents and 98% of professionals agreed that better communication between families and providers is needed (Keenan et al., 2010).

Chamak et al. (2011) surveyed 248 French parents about their experiences with ASD diagnostic evaluations conducted between 1960 and 2005. The findings of this study suggested that both diagnostic delays and parental dissatisfaction reduced over time. Specifically, of the parents who completed the evaluation between 1960–1989, 93% reported dissatisfaction with the process, stating that they encountered major challenges when trying to obtain the diagnosis, experienced breaches in privacy and confidentiality, and disclosed that some providers made blunt statements that further enhanced parental guilt (Chamak et al., 2011). In contrast, only 63% of parents whose child was diagnosed between 1990–2005 reported some level of dissatisfaction, most commonly describing the need for more information, support, and school integration after receiving the diagnosis.

When investigating what information is being shared with parents following the provision of ASD diagnosis, Rhoades et al. (2007) examined data from 146 caregivers of children with ASD. They found that 40% of professionals provided additional information about ASD, 34% advised on medical/educational programs, 6% referred the parents to ASD specialists, and 18% provided no further information. Parents also reported that they most commonly sought additional resources and information via media (i.e., the internet, books, videos), followed by conferences and other parents.

Similar findings were reported by Osborne and Reed (2008) who interviewed parents in UK autism focus groups and found that most diagnostic evaluations were completed by medical providers, followed by psychologists, and speech pathologists. Among the most common factors leading to diagnosis included behavioral problems, language, perseveration, and developmental

differences. Concerning feedback, 30% reported receiving professional advice about autism, 29% reported receiving no or very little information/support, 16% received leaflets/books, and 24% of parents reported that they obtained the information/support for themselves. Additionally, when asked what parents found helpful about the process, 38% reported feeling relief/confirmation, 26% reported a feeling of being understood, 7% reported that the process helped to alter their expectations, and 29% of parents did not find the process helpful. When asked what could be improved, 39% of parents stated that the standardization and speed could be increased, 21% reported the need for more information about available organizations and services, 18% indicated a desire for receiving more support/help (i.e., counseling services), 16% wished for more information about autism, and 5% stated that they could use more concrete information about how to deal with the child's behaviors. Among the recommended services belonged educational help (26%), intervention packages (14%), medical help/nurse visit (15%), review with a professional (6%), respite care (3%), and 36% of parents reported receiving no service recommendations. Lastly, 62% of parents believed that recommendations should be given immediately after the diagnosis, 8% after "some months," and 30% would like to receive phased/follow-up recommendations. Overall, Osborne & Reed (2008) suggest that key a successful feedback session consists of two main components: (1) personal connection with the family and (2) openness/honesty of the provider.

A similar approach was utilized by Mansell and Morris (2004) who surveyed 109 parents whose child was diagnosed with ASD between 1995–1999, evaluating whether changes in district diagnostic service within the UK lead to improvements in parental experiences with the process. Overall, the results suggested that parental perceptions have been improving over time, which may be due to the changes in the system (i.e., the inclusion of a liaison throughout the

diagnostic process). Nonetheless, while parents believed that the diagnostic terms were explained well during the feedback, more than 50% reported feeling that recommendations regarding sources of information, treatment, and coping strategies were explained slightly well or not well at all. Some of the commonly cited recommendations for professionals were providing resources about counseling services for parents, avoiding giving “too bleak” prognosis, discussing available support and treatment options (before, during, and after providing diagnosis), reducing waitlist, providing more information about dietary options and school accommodations, and reassuring parents that there are things they can do to help the child (Mansell & Morris, 2004).

Furthermore, Gaspar de Alba and Bodfish (2011) investigated concerns at the time of receiving an autism diagnosis, collecting responses from 438 parents. The results showed that at the time of diagnosis, parents were primarily concerned about the core ASD symptoms (i.e., language delays, problematic patterns of behaviors, and limited social skills). The most commonly cited medical concerns were related to the child’s sleep, eating, and gastrointestinal problems. Only about half of the parents believed that the professionals addressed concerns with core ASD symptoms sufficiently, and only about a third believed that the professionals addressed non-core ASD concerns sufficiently. The parents further believed that the area of greatest focus should be discussing available treatment options, while significantly fewer parents reported the need to discuss future expectations for the child, the level of child’s cognitive ability, ASD etiology, and risk for siblings. Interestingly, parents of boys were significantly more concerned about the child’s social problems than parents of girls, and with increasing age of the child, parents also tended to report more concerns about sleep, social problems, and unwanted behaviors while concerns about language development decreased (Gaspar de Alba & Bodfish, 2011). Such results are consistent with the findings of Whitaker (2002) who showed that parents

of preschoolers diagnosed with autism particularly valued a clear presentation of information about ASD, professional support when “making sense” of the child’s development, and practical strategies for the development of language and play skills.

Lastly, Whaley (2007) developed a study evaluating factors influencing parental satisfaction with autism evaluation across ten US states. Responses from 84 parents were collected, showing that before the feedback session, 45% of parents expected to receive an autism diagnosis, 44% expected delays but not autism, and almost 11% did not believe that their child will be given any diagnosis. The average rating of overall satisfaction with the feedback was 3 on a 5-point scale. There was also a significant relationship between parental satisfaction and clarification of the diagnosis ($r = .52$), discussion of child’s strengths ($r = .66$), discussion of positive aspects of autism ($r = .57$), value of parental input ($r = .59$), discussion of future expectations ($r = .42$), treatment options ($r = .66$), provision of educational materials ($r = .49$), and parental comfort with asking questions during the feedback session ($r = .54$). When asked to indicate which characteristics the providers demonstrated, parents most commonly selected realistic (64.3%), compassionate (61.9%), open to listening (59.5%), and understanding (55.9%). The least frequent provider characteristics were anxious and tense (6.0%). Additionally, some parents shared that the providers seemed cold, condescending, business-like, embarrassed, positive, and knowledgeable (Whaley, 2007).

It is important to mention that while many of the above-mentioned studies suggest general dissatisfaction with the ASD evaluation process, there are additional factors that can further contribute to negative experiences and perceptions of ASD assessment and feedback among caregivers. Specifically, socioeconomic status, race/ethnicity, rurality, level of education, and primary household language were all found to negatively impact access to appropriate health

services (Hartley, 2004; Kalkbrenner et al., 2011; Streeter et al., 2020), which may in turn further contribute to client dissatisfaction with ASD evaluation process. For example, Martinez et al. (2018) researched systematic barriers that make receiving the ASD diagnosis in young children more challenging. Collecting data from 450 families, they found that families who had to travel 60+ miles for the diagnostic assessment were more likely to receive shifting diagnoses and see 3+ professionals over the course of the diagnostic process. Families who reported difficulties finding a psychologist/psychiatrist were more likely covered by public insurance, experienced diagnostic delays of 24+ months, and were more likely to be told that their child does not have ASD.

Interestingly, Martinez et al. (2018) also found that the older age of the child, as well as race/ethnic minority identity, were associated with lower odds of delay in diagnosis. This result is consistent with the finding showing that, within the United States, there is a diagnostic disparity based on race, ethnicity, and primary household language, as children belonging to ethnic/racial minority groups are less likely to be diagnosed with ASD than non-Hispanic white children (Jo et al., 2015).

The idea that racial/ethnic identity and primary household language may be associated with hindered access to timely ASD diagnosis was further supported by Zuckerman et al. (2014). Their study included a sample of 33 primarily Spanish-speaking parents who identified as Latinx/Mexican origin. Most of the participants reported that stigma, limited English proficiency, poor awareness of available services, lack of empowerment, and low financial resources prevented them from seeking care for their children and themselves (Zuckerman et al., 2014). Caregiver experiences with health care providers were also mixed as several parents reported believing that their concerns were dismissed incorrectly, which resulted in the need to visit

multiple specialists and travel long distances before receiving the diagnosis. In relation to feedback, parents stated that even after receiving the diagnosis, they were often unsure what ASD meant or what they should do (Zuckerman et al., 2014).

Lastly, population density is one of the most commonly cited barriers to receiving the ASD diagnosis, even though ASD prevalence is thought to be similar between rural (0.9%) and urban (1.0%) areas (Mohamed et al., 2016). Families in rural areas often experience difficulties when accessing professional services due to a scarcity of specialists and early intervention programs (Antezana et al., 2017; Kalkbrenner et al., 2011), leading to an average diagnostic delay of 0.4–0.9 years compared to children living in urban areas (Mandell et al., 2005). One study that investigated parental experiences with ASD evaluation in rural New England showed that the diagnostic delays ranged from 6 months to 10 years, with the majority of parents receiving the diagnosis within 3 years following their initial concern (Hutton & Caron, 2005). Many parents also reported undergoing numerous referrals, and, in some cases, the children were inaccurately diagnosed (e.g., ADHD, obsessive-compulsive disorder; Hutton & Caron, 2005).

Current Study

Considering the overall finding that there is currently not a unitary approach to ASD feedback delivery and that parents often find the process distressing (Farrugia, 2009; Midence & O'Neill, 1999; Ooi, et al., 2016; Whaley, 2007) and unsatisfactory (Brogan & Knussen, 2003; Chamak et al., 2011; Howlin & Moore, 1997; Keenan et al., 2010), the current study aimed to investigate caregiver experiences and perceptions of ASD feedback process. Specifically, the primary goal of the study was to explore factors that may be influencing caregiver satisfaction. Building on the previous literature, we planned to evaluate how factors such as the diagnostic process, provider's characteristics, and the level of caregiver emotional distress relate to

feedback satisfaction. Since previous studies also suggested that certain demographic factors may act as barriers to receiving an ASD diagnosis (Hutton & Caron, 2005; Jo et al., 2015; Martinez et al., 2018; Zuckerman et al., 2014), we further aimed to evaluate whether access to health care and racial minority status can impact satisfaction with feedback.

The second goal of the study was to investigate the extent of variability in ASD feedback practices across providers within the United States as reported by caregivers. As the number of recent studies describing the feedback session is limited, our study planned to minimize this gap in the literature by reporting the most common aspects of the feedback process such as the average length of the feedback session, the most frequent elements included in the feedback process, and barriers to recommendation follow-through.

Hypotheses

The current study included 12 hypotheses investigating factors contributing to feedback satisfaction such as family characteristics, evaluation process, provider characteristics, and emotional distress following the provision of ASD diagnosis.

Table 1

List of Hypotheses

Family Characteristics

Hypothesis 1	Caregivers located in Health Professional Shortage Areas (HPSA) will have lower feedback satisfaction
Hypothesis 2	Caregiver's racial/ethnic minority status will be associated with lower feedback satisfaction

Process

Hypothesis 3	Longer waitlist will be associated with lower feedback satisfaction
Hypothesis 4	Usage of caregiver report measures during the assessment will be associated with greater feedback satisfaction
Hypothesis 5	Feedback session length will be associated with feedback satisfaction

Hypothesis 6 Presence of others during feedback (i.e., family members, friends) will be associated with greater feedback satisfaction

Provider Characteristics

Hypothesis 7 Higher perceived provider's helpfulness will be associated with greater feedback satisfaction

Hypothesis 8 Higher perceived provider's advocacy will be associated with greater feedback satisfaction

Hypothesis 9 Higher perceived provider's sensitivity will be associated with greater feedback satisfaction

Hypothesis 10 Higher value of caregiver input by the provider will be associated with greater feedback satisfaction

Emotional Distress

Hypothesis 11 Higher emotional distress symptom count will be associated with lower feedback satisfaction

Hypothesis 12 Higher valence of emotional distress will be associated with lower feedback satisfaction

Methods

Participants

The current study collected data through the Qualtrics online survey system. Participants were recruited nationwide through multiple means including social media posts on researchers' personal accounts (i.e., Facebook, Instagram), paid advertisement on Facebook social media platform, and sharing the study advertisement with colleagues from four US-based university programs and centers focused on research and clinical work with individuals diagnosed with neurodevelopmental disabilities. The study required participants to be at least 18 years old, be a caregiver to at least one child who was diagnosed with ASD, have past participation in the diagnostic and feedback process, have internet access, reside in the United States, and have English proficiency sufficient to complete the survey. Furthermore, since the aim of the current study was to evaluate diagnostic practices that are reflective of the DSM-5 criteria for ASD, the

current study excluded responses from participants whose child was diagnosed before 2013. Additionally, participants whose child was 18 years or older at the time of the diagnosis were excluded from the study.

A study by Whaley (2007) investigating factors influencing parental satisfaction with autism evaluation in the US included 84 participants, reporting moderate to large correlations ($r = .53-.72$) between the overall satisfaction score and factors such as providers characteristics and level of perceived support. Considering these findings, our initial power analysis for multiple regression with 15 predictors ($\alpha = .05$, power = .80) using the G*power statistical software (Faul et al., 2007) indicated that approximately 139 participants would be needed in total to obtain a moderate effect size $f^2 = 0.15$. The current study collected responses from 330 participants. Data collection was completed in June 2021. Following the clean-up procedure which included deletion of duplicate and counterfeit responses, incomplete responses with more than 20% of missing data, as well as responses that did not correctly complete attention checks, a total sample size of 268 participants was included in the data analysis.

Altogether, participants from 45 states were included in the current sample (i.e., AK, AL, AR, AZ, CA, CO, CT, DE, FL, GA, HI, IA, ID, IL, IN, KS, KY, LA, MA, MD, ME, MI, MO, MT, NC, NE, NH, NJ, NM, NV, NY, OH, OK, OR, PA, RI, SC, TN, TX, UT, VA, VT, WA, WI, WV). Participant distribution ($N = 267$) across the U.S. regions was as follows: Northeast 15.73% ($n = 42$), Midwest 27.34% ($n = 73$), South 34.83% ($n = 93$), West 20.97% ($n = 56$), and Pacific 0.01% ($n = 3$). The average caregiver age at the time of receiving the child's ASD diagnosis was 36.14 years ($SD = 8.11$). 225 caregivers identified as female, 40 as male, and 2 as non-binary or transgender. In terms of ethnic and racial identity, 195 caregivers identified as White Non-Hispanic/Latinx, and 72 caregivers identified as belonging to either a racial or ethnic

minority. Additionally, the average age of the child receiving the ASD diagnosis was 5.98 years ($SD = 3.67$) at the time of the feedback. Per the caregiver report, 83 children identified as female, 181 as male, and 4 as non-binary or transgender. Caregivers further reported that 178 children identified as White Non-Hispanic/Latinx, and 90 children identified as belonging to either a racial or ethnic minority. For more information about the caregiver and child characteristics, please see Table 2 and Table 3, respectively.

Table 2

Caregiver Demographic Information

Demographic Categories	<i>n</i>	%
Gender		
Male	40	15.0
Female	225	84.3
Non-binary/Transgender	2	0.7
<i>Total</i>	<i>267</i>	<i>100.0</i>
Racial Identity		
White/Caucasian	232	86.6
Black/African American	23	8.6
Native American/Alaska Native	16	6.0
Asian	1	0.4
Hawaiian Native/Pacific Islander	2	0.7
Other	5	1.9
<i>Total</i>	<i>268</i>	<i>100.0</i>
Ethnic Identity		
Hispanic/Latinx	49	18.6
Non-Hispanic/Latinx	213	81.0
<i>Total</i>	<i>263</i>	<i>100.0</i>
Relationship to Child		
Biological Mother	199	74.3
Biological Father	34	12.7
Adoptive/Foster Mother	12	4.5
Adoptive/Foster Father	3	1.1
Stepmother	1	0.4
Grandmother	16	6.0
Other	3	1.1
<i>Total</i>	<i>268</i>	<i>100.0</i>
Level of Education		
Less Than High School	7	2.6

High School Graduate	48	17.9
Some College	84	31.3
2-year Degree	50	18.7
4-year Degree	44	16.4
Professional Degree	30	11.2
Doctorate	5	1.9
<i>Total</i>	<i>268</i>	<i>100.0</i>

Table 3

Child Demographic Information

Demographic Categories	<i>n</i>	%
Gender		
Male	181	67.5
Female	83	31.0
Non-binary/Transgender	4	1.5
<i>Total</i>	<i>268</i>	<i>100.0</i>
Racial Identity		
White/Caucasian	238	88.8
Black/African American	30	11.2
Native American/Alaska Native	16	6.0
Asian	3	1.1
Hawaiian Native/Pacific Islander	1	0.4
Other	8	3.0
<i>Total</i>	<i>268</i>	<i>100.0</i>
Ethnic Identity		
Hispanic/Latinx	60	22.8
Non-Hispanic/Latinx	201	76.4
<i>Total</i>	<i>263</i>	<i>100.0</i>

Additional family demographic information was collected to obtain a better understanding of the sample's socio-economical standing at the time of completing the child's ASD evaluation and feedback. The details are summarized in Table 4, but caregivers most commonly reported having a household size of 3 individuals (38.6%), with a total household yearly income lower than \$25,000 (24.6%), and finances sometimes being a stressor (28.8%).

Table 4

Additional Family Characteristics

Demographic Categories	<i>n</i>	%
Total Yearly Household Income		
Less than \$25,000	66	24.6
\$25,000-\$34,999	52	19.4
\$35,000-\$49,999	50	18.7
\$50,000-\$74,999	55	20.5
\$75,000-\$99,999	26	9.7
\$100,000-\$149,999	10	3.7
\$150,000 or more	9	3.4
<i>Total</i>	<i>268</i>	<i>100.0</i>
How Often Were Finances a Stressor		
Never	18	6.7
Sometimes	77	28.8
About half the time	62	23.2
Most of the time	68	25.5
Always	42	15.7
<i>Total</i>	<i>267</i>	<i>100.0</i>
Household Size		
Two	20	7.5
Three	103	38.6
Four	83	31.1
Five	38	14.2
Six	12	4.5
Seven	8	3.0
Eight or more	3	1.1
<i>Total</i>	<i>267</i>	<i>100.0</i>

Materials

Due to the lack of an available validated measure that would effectively cover the proposed research questions, an online survey was created by the researchers (see Appendix 1). It should be noted that, for the purposes of a different research project, the survey included additional questions that were not utilized by the current study as they were not relevant to the proposed research questions. The questions included in the survey that were specific to the feedback process built on past research by Osborne and Reed (2008), Mansell and Morris (2004),

and Whaley (2007), who showed an association between caregiver satisfaction with the diagnostic process and factors such as provider characteristics and provided recommendations. The questions regarding the feedback process included within the survey were also inspired by recommendations included in the Provider's Guide to Providing Effective Feedback to Families Affected by Autism and Feedback Session Quality Checklist (Austin et al., 2012).

Additionally, the questions assessing caregiver feedback satisfaction were adapted from the Client Satisfaction Questionnaire (CSQ-3; Larsen et al., 1979), which is a validated tool commonly used for the assessment of customer satisfaction with services. CSQ-3 is an abbreviated measure that uses three core items from the full version (CSQ-8) that were found to be the most empirically salient when measuring client satisfaction (Larsen et al., 1979). The three questions were previously used by Krahn, Eisert, and Fifield (1990) to measure caregiver satisfaction with case management services provided to their children with developmental disabilities (Cronbach's $\alpha = .78, .82, \text{ and } .80$). For the purpose of the current study, the language of the three questions was modified by exchanging "our program/service" for "feedback." Furthermore, instead of the original 4-point scale, a continuous rating scale with four anchors and a draggable slider was utilized to allow for a greater range.

The survey consisted of three sections. The first section collected information about the caregiver's and child's demographics including gender, race/ethnicity, age of the child and the caregiver at the time of the evaluation, caregiver level of education, financial stress, family income, household size, and the family's home zip code when completing the evaluation. The second section inquired about the assessment process that families received. Specifically, the caregivers will be asked to report on their experiences prior to the evaluation (e.g., at what age they started noticing symptoms, who referred them for the evaluation, and how easy it was for

the family to find a provider) and during the evaluation (e.g., the combined length of the assessment sessions, the involvement of other reporters, and consideration of caregiver's observations and concerns). While most of the questions in this section were irrelevant to the current study, two questions asking about the length of the waitlist and the type of utilized measures were included in the current data analyses.

The last section of the online survey focused on the feedback. This section included questions about the process (e.g., length, provision and discussion of the written report, discussion of the provided diagnoses, the inclusion of psychoeducation about ASD, provision of recommendations/referrals/additional resources, opportunity to ask questions and process the impact of provided diagnosis within the session), questions about the provider characteristics, caregiver's emotional response, caregiver satisfaction with the feedback process, and barriers to follow through with the provided recommendations.

Procedure

The survey was accessible online through a web link advertised/posted on the designated websites. Caregivers who wanted to take part in the proposed study were first familiarized with its purpose and asked to review the inclusion criteria. Once the participants provided informed consent to participate, they were asked to complete the online Qualtrics survey. In case the participant was a caregiver to more than one child diagnosed with ASD, the participant was instructed to report on their first experience with ASD evaluation. Doing so allowed us to collect data from caregivers previously unfamiliar with the ASD diagnostic and feedback process. The survey further included four attention checks designed to evaluate the participants' attentiveness to question content while completing the survey. Participants who fail to provide correct answers to any of the attention checks were excluded from the study. Upon survey completion, the

caregivers were provided with the opportunity to enter a raffle for \$50 Amazon Gift cards with chances of winning 1:25 as an incentive for participation. To preserve the confidentiality of the provided responses, the participant contact information was collected through a separate survey link.

Data Analyses

Participants who did not meet the inclusion criteria or failed any of the four attention checks were removed from the dataset. The Statistical Package for the Social Sciences (SPSS) program was used for the statistical analyses (IBM Corporation, 2017). Hypotheses 1–12 were analyzed using multiple regression, which is a highly flexible analytic system that can be used in practical prediction problems whose goal is to forecast an outcome based on previously collected data (Cohen et al., 2015). The analysis included 15 predictor variables, and one continuous outcome variable “Feedback Satisfaction” ranging from 0-100. This score was calculated by averaging the scores from the survey questions that were adapted from CSQ-3 (i.e., Appendix 1 Q4.12, Q4.16, and Q4.17), all utilizing continuous rating scales with draggable sliders ranging from 0-100. There was a high internal consistency among the three scales (Cronbach’s Alpha = .88). The mean score for Q4.12 was 71.71 (SD = 23.16), mean score for Q4.16 was 68.27 (SD = 23.00), and the mean for Q4.17 was 73.19 (SD = 27.88). Missing data on these scales were addressed using multiple imputation (MI), which fills in missing cases by generating estimated values and the related variances from distributions and relationships among observed variables, reducing the chances of committing Type I and II errors (Li et al., 2015). List-wise deletion was used to address missing values on the predictor variables since they are mostly single-item variables that cannot be effectively imputed using MI. Dummy coding was used for ordinal

predictor (i.e., Length of Feedback Session) and nominal covariate variables (i.e., Child Gender, Caregiver Gender, Relationship to Child).

The Health Professional Shortage Areas (HPSA) Score for Hypothesis 1 was obtained from the Health Resources and Services Administration database using the caregiver's home ZIP code at the time of diagnosis (HPSA Find, n.d.). The HPSA scores range from 0–25, with a higher score indicating a greater shortage of health care providers in the specific geographical location (Health Professional Shortage Areas, 2020). Nonetheless, given that range of HPSA scores within the current sample was not satisfactory for the proposed analyses, the HPSA variable was treated as dichotomous (i.e., 0 = Not located in an HPSA; 1 = located within an HPSA area). A similar approach was used for Hypothesis 2, proposing that caregivers' racial/ethnic minority status will be associated with lower feedback satisfaction. While more comprehensive data about the caregivers' racial and ethnic identity were collected and could be used for future analyses, the current study combined the collected data into two groups (i.e., 0 = caregivers identifying as white, non-Hispanic/Latinx; 1 = caregivers who identify as belonging to any racial and/or ethnic minority group or those who identify as multiracial) to compensate for the limited number of participants across all racial and ethnic minority groups.

Furthermore, the Provider Characteristics Total Score for Hypothesis 7 was calculated by subtracting the number of selected provider characteristics that the caregivers found unhelpful from the number of selected provider characteristics that the caregivers found helpful, with higher scores suggesting more positive caregiver perception of provider characteristics during the feedback. Lastly, the Emotional Distress Count Score was calculated by adding the number of selected emotions commonly perceived as negative on Question 4.13 (see Appendix 1). The

Emotional Distress Count Score ranged 0–12, with higher scores suggesting a higher number of distressing emotions the caregiver experienced during the feedback process.

Results

Assumptions

All continuous variables were tested for normality using the Z-test with a recommended alpha level of .01 (± 2.58) for large samples ($n > 200$; Ghasemi & Zahediasl, 2012). When appropriate, offending variables were transformed. Using Log10 transformation, Waitlist Length (i.e., H3) fell within the acceptable normality limits with a skewness of .37 ($SE = .15$) and kurtosis of .12 ($SE = .30$), Provider Helpfulness (i.e., H7) with a skewness of -.10 ($SE = .16$) and kurtosis of .05 ($SE = .32$), and Distress Count (i.e., H11) with a skewness of -.21 ($SE = .15$) and kurtosis of -.83 ($SE = .30$). For the outcome variable (i.e., Feedback Satisfaction) and three predictor variables (i.e., H8 – Provider Advocacy; H9 – Provider Sensitivity, and H10 – Caregiver Input), any type of transformation did not yield satisfactory results and the variables were thus used in their original form. It should also be noted that through visual inspection of standardized regression residuals, the distribution of the Feedback Satisfaction variable was satisfactory. Distress Valence (i.e., H12) variable showed acceptable limits with skewness of -.35 ($SE = .15$) and kurtosis of -.81 ($SE = .30$) and thus was not transformed.

Normality was also assessed in three additional continuous variables (i.e., Time since diagnosis, Child's age at the time of diagnosis, and Caregiver's age at the time of diagnosis). The transformation process did not yield satisfactory results for the Time since Diagnosis variable, and thus the decision to carry on with analyses using the original variable was made. Square root transformation was used for Child's Age, yielding acceptable skewness of .27 ($SE = .15$) and kurtosis of -.91 ($SE = .30$). Log10 transformation was used for Caregiver's Age, showing

skewness of .48 ($SE = .15$) and kurtosis of .01 ($SE = .31$). Furthermore, the assumptions of linearity and homoscedasticity were met within the multiple regression model as assessed by visual inspection of a plot of studentized residuals versus unstandardized predicted values. The Feedback Satisfaction variable included two outlier points, which did not have large influence and leverage values and were not considered to be a result of measurement error. Retrospective testing revealed that exclusion of the outlier points within our analyses did not lead to significant differences in the findings. The assumption of the absence of multicollinearity was also met as all Variance Inflation Factor (VIF) values were below 10. Therefore, all assumptions for multiple regression model were met.

Table 5

Descriptive Statistics – All Continuous Variables Before Transformation

	<i>N</i>	Observed		Mean	<i>SD</i>	Skewness Z-Score	Kurtosis Z-Score
		Min	Max				
Feedback Satisfaction	286	0	100	71.08	22.33	-6.16	2.30
Waitlist Length (mo.)	266	0	24	4.01	3.87	17.30	29.86
Provider Helpfulness	236	-6	12	4.97	4.16	-4.48	0.59
Provider Advocacy	266	0	100	71.70	24.43	-5.49	1.46
Provider Sensitivity	268	0	100	68.97	27.37	-4.74	-1.11
Caregiver Input	268	0	100	73.75	23.76	-6.26	2.12
Distress Count	268	0	12	2.91	2.66	7.99	4.22
Distress Valence	267	0	100	55.05	28.35	-2.36	-2.74
Time since Diagnosis (yr.)	268	0	8	3.22	2.13	3.66	-0.00
Caregiver's Age (yr.)	251	22	63	36.14	8.11	6.75	2.98
Child's Age (yr.)	268	1	16	5.98	3.67	4.90	-1.36

Note. *N* = sample size, *SD* = standard deviation

Predicted Covariates

In addition to the main predictor variables, six variables (i.e., Time since Diagnosis, Child's Age at the Time of Diagnosis, Child's Gender, Caregiver's Age at the Time of Diagnosis, Caregiver's Gender, and Caregiver's Relationship to the Child) were tested in order to determine whether they should be included in the regression model as covariates. While Time since

Diagnosis, Child's Age at the Time of Diagnosis, and Caregiver's Age at the Time of Diagnosis were continuous variables (see Table 5), Child's and Caregiver's Gender were discrete variables with three categories (i.e., Male, Female, and Non-binary/Transgender). Similarly, the Caregiver's Relationship to Child variable was also discrete with three categories (i.e., Biological Mother, Biological Father, and Other). The multiple regression model with all potential covariate variables revealed multicollinearity among Caregiver's Gender (female), Child's Gender (male), and Relationship to Child (biological mother) with VIF values above 10. These variables were thus automatically excluded. The overall results indicated that none of the variables were statistically significant predictors of feedback satisfaction, and they were thus dropped from the final regression model.

Table 6

Predicted Covariate Variables and Feedback Satisfaction

	<i>B</i>	<i>SE B</i>	β	<i>t</i>	<i>p</i>
Time since Diagnosis	-.71	.40	-.07	-1.79	.075
Child's Age	.92	1.17	.03	.79	.433
Child's Gender (female)	1.48	1.78	.03	.83	.407
Child's Gender (non-binary/trans)	-3.12	8.29	-.02	-.38	.707
Caregiver's Age	15.19	10.94	.06	1.39	.167
Caregiver's Gender (male)	.61	4.84	.01	.13	.899
Caregiver's Gender (non-binary/trans)	2.28	14.36	.01	.16	.874
Relationship to Child (biological mother)	5.71	5.05	.09	1.13	.260
Relationship to Child (biological father)	.23	2.94	.00	.08	.938

Note. *B* = unstandardized regression coefficient; *SE B* = standard error of the coefficient; β = standardized coefficient.

Multiple Regression Model

A standard multiple regression was run to determine the relationship between the 15 main predictor variables and the Feedback Satisfaction outcome variable. For directional hypotheses, the provided *p*-values are one-tailed. R^2 for the overall model was 75.0% with an adjusted R^2 of

73.3%, a large size effect according to Cohen (1988). The results indicated that the 15 predictor variables included in the model were significantly related to feedback satisfaction, $F(14, 211) = 45.23, p < .001$. Regression coefficients and standard errors can be found in Table 7 and partial and semi-partial correlations in Table 8. The regression coefficients are interpreted with all values of all other independent variables being held constant. Regarding Hypothesis 1, the caregiver's HPSA location at the time of the child's diagnosis was not significantly related to lower feedback satisfaction, $t = 1.46, p = .075$. The predicted feedback satisfaction for caregivers located within HPSA locations was on average 2.87% greater than for those living outside of HPSA locations. For Hypothesis 2, the caregiver's racial/ethnic minority status was not significantly related to lower feedback satisfaction, $t = -.45, p = .327$. On average, the predicted feedback satisfaction for caregivers who identified as White, Non-Hispanic/Latinx was .76% lower than for caregivers who identified as multiracial or belonging to a racial and/or ethnic minority. Hypothesis 3 predicted that a longer waitlist will be associated with lower feedback satisfaction, which was supported by the data, suggesting that there is a statistically significant relationship between feedback satisfaction and waitlist length, $t = -2.69, p = .004$. Specifically, an increase in waitlist length by 1 unit was associated with a decrease in feedback satisfaction by 7.80%.

Next, for Hypothesis 4, usage of caregiver report measures during assessment was not significantly associated with higher feedback satisfaction, $t = -.11, p = .459$. On average, the feedback satisfaction was .18% lower in caregivers who endorsed using caregiver report measures during the assessment process ($n = 197$) compared to those who did not endorse using these measures ($n = 71$). Hypothesis 5 proposed that the length of feedback session will be associated with feedback satisfaction, which was not supported by the current findings for any of

the feedback session length categories (i.e., 31-60 min, $t = -.06$, $p = .950$; 61-90 min, $t = .19$, $p = .849$; 91+ min, $t = 1.50$, $p = .137$). Hypothesis 6 also yielded non-significant findings, as the presence of others during the feedback session was not associated with feedback satisfaction $t = 1.11$, $p = .310$. The presence of others (e.g., family members, friends; $n = 221$) was associated with 2.05% greater feedback satisfaction compared to when nobody else was present ($n = 45$) during the feedback session.

Furthermore, Hypothesis 7 proposed that higher perceived provider helpfulness will be significantly related to greater feedback satisfaction, which was not supported by the current findings, $t = .11$, $p = .457$. An increase in the perceived provider helpfulness by 1 unit was associated with an increase in feedback satisfaction by 0.76%. Nonetheless, the current regression model supported Hypothesis 8, predicting that higher perceived provider advocacy will be associated with greater feedback satisfaction, $t = 4.82$, $p < .001$. An increase in the perceived provider's advocacy by 1 unit was associated with an increase in feedback satisfaction by 0.30%. In contrast, higher perceived provider sensitivity was not associated with greater feedback satisfaction as proposed by Hypothesis 9, $t = 1.16$, $p = .123$. As the perceived provider's sensitivity increased by 1 unit, feedback satisfaction increased by 0.06%.

In regard to Hypothesis 10, the findings indicated that a higher value of caregiver's input by the provider was related to greater feedback satisfaction $t = 6.69$, $p < .001$. An increase in the perceived value of caregiver's input by 1 unit was associated with an increase in feedback satisfaction by 0.40%. Hypothesis 11 also yielded significant findings, suggesting that greater emotional distress symptoms count was associated with lower feedback satisfaction, $t = -2.99$, $p = .002$. Specifically, an increase in caregiver's emotional distress count by 1 unit was associated with a decrease in feedback satisfaction by 9%. Lastly, higher emotional distress valence was not

significantly related to lower feedback satisfaction, $t = 1.25$, $p = .107$, as proposed by Hypothesis

12. An increase in caregiver's emotional distress valence by 1 unit was associated with an increase in feedback satisfaction by 0.04%.

Table 7

Multiple Regression Results for Feedback Satisfaction

	<i>B</i>	<i>95% CI</i>		<i>SE B</i>	β	R^2	ΔR^2
		<i>LL</i>	<i>UL</i>				
Model						.75	.73***
Constant	20.68*	.41	40.94	10.28			
HPSA Location	2.87	-1.01	6.75	1.97	.05		
Racial/Ethnic Minority	-.76	-4.11	2.58	1.70	-.02		
Waitlist Length	-7.80**	-13.52	-2.08	2.90	-.10**		
Caregiver Report Use	-.18	-3.52	3.17	1.70	.00		
Feedback Length 31-60 min	-.11	-3.64	3.42	1.79	.00		
Feedback Length 61-90 min	.50	-4.63	5.62	2.60	.01		
Feedback Length 91+ min	9.89	-3.18	22.96	6.63	.05		
Presence of Others	2.05	-1.92	6.03	2.02	.04		
Provider Helpfulness	.76	-13.20	14.73	7.09	.01		
Provider Advocacy	.30***	.18	.43	.06	.35***		
Provider Sensitivity	.06	-.04	.16	.05	.08		
Value of Caregiver Input	.40***	.29	.52	.06	.45***		
Emotional Distress Count	-9.00**	-14.94	-3.07	3.01	-.13**		
Emotional Distress Valence	.04	-.02	.11	.03	.05		

Note. Model = "Enter" method in SPSS Statistics; *B* = unstandardized regression coefficient; *CI* = confidence interval; *LL* = lower limit; *UL* = upper limit; *SE B* = standard error of the coefficient; β = standardized coefficient; R^2 = coefficient of determination; ΔR^2 = adjusted R^2 .

* $p < .05$. ** $p < .01$. *** $p < .001$.

Table 8

Partial and Semi-Partial Correlation Coefficients

	<i>Partial</i>	<i>Semi-Partial</i>
HPSA Location	.10	.05
Racial/Ethnic Minority	-.03	-.02
Waitlist Length	-.23	-.18
Caregiver Report Use	-.01	.00
Feedback Length 31-60 min	.00	.00
Feedback Length 61-90 min	.01	.01

Feedback Length 91+ min	.10	.05
Presence of Others	.07	.04
Provider Helpfulness	.01	.00
Provider Advocacy	.32	.17
Provider Sensitivity	.08	.04
Caregiver Input	.42	.23
Emotional Count	-.20	-.10
Emotional Valence	.09	.04

When controlling for the rates of Type I error, the current study employed the false discovery rate (FDR) approach over the familywise error rate (FWER) approach. Since FDR allows for controlling the proportion of significant results that are Type I errors instead of controlling for the chance of making even a single Type I error, it is thought to be less conservative than the traditional Bonferroni correction (Verhoeven, 2015). The results of FDR indicated that Waitlist Length, Provider Advocacy, Value of Caregiver Input, and Emotional Distress Count were all significant predictors of feedback satisfaction ($m = 15$; $q = .05$).

Non-Parametric Correlations

Due to concerns related to the satisfaction of the normality assumption within our multiple regression model, Spearman's correlation was completed to further evaluate the strength and direction of the relationship among our variables. Original, untransformed variables and list-wise deletion were utilized for this analysis. Overall, the results of the non-parametric test were consistent with the findings of the multiple regression model, producing significant correlations between Feedback Satisfaction and Waitlist Length ($r = -.18$, $p = .008$), Provider Advocacy ($r = .27$, $p < .001$), Value of Caregiver Input ($r = .33$, $p < .001$), and Emotional Distress Count ($r = -.22$, $p = .001$). While significant correlations were also initially found among Feedback Satisfaction and Feedback Length ($\rho = .13$, $p = .047$), Provider Helpfulness ($\rho = .48$, $p < .001$),

and Provider Sensitivity ($\rho = .72, p < .001$) variables (see Table 9), these relationships were non-significant while controlling for the influence of the remaining predictor variables (see Table 10).

Table 9

Spearman's (ρ) Correlation

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. Feedback Satisfaction	-											
2. HPSA Location	-.01	-										
3. Racial/Ethnic Minority	-.06	.18**	-									
4. Waitlist Length	-.19**	.06	.19**	-								
5. Caregiver Report Use	.05	-.03	.09	.04	-							
6. Feedback Length	.13*	.09	-.05	.11	.05	-						
7. Presence of Others	.05	-.01	-.13*	-.02	-.03	.09	-					
8. Provider Helpfulness	.48***	-.09	.04	-.07	.05	-.07	-.11	-				
9. Provider Advocacy	.79***	-.03	-.05	-.10	.06	.15*	.03	.57***	-			
10. Provider Sensitivity	.72***	.02	-.04	-.06	.02	.24***	.03	.53***	.84***	-		
11. Caregiver Input	.78***	-.05	-.03	-.07	.07	.17*	.00	.55***	.85***	.80***	-	
12. Emotional Count	-.14*	.00	-.10	-.01	-.01	-.06	-.09	-.06	-.05	-.07	-.01	-
13. Emotional Valence	-.02	.02	-.07	-.13	-.17	-.01	-.07	.00	.00	-.03	-.03	.52***

Note. Sig. 2-tailed * $p < .05$. ** $p < .01$. *** $p < .001$.

Table 10

Partial Correlation Coefficients

	Feedback Satisfaction	p
HPSA Location	.05	.467
Racial/Ethnic Minority	-.04	.593
Waitlist Length	-.18	.008
Caregiver Report Use	.03	.633
Feedback Length	-.03	.659
Presence of Others	.03	.636

Provider Helpfulness	-.01	.873
Provider Advocacy	.27	.000
Provider Sensitivity	.11	.119
Caregiver Input	.33	.000
Emotional Count	-.22	.001
Emotional Valence	.10	.164

Note. $df = 213$.

Additional Analyses

In addition to the primary hypotheses tested through the multiple regression model, the current study aimed to also provide information about the ASD feedback practices within the United States as reported by the caregivers. The findings from the current sample indicate that 30.6% of caregivers had feedback sessions shorter than 30 min, and the most frequent length of feedback sessions was 31-60 min (54.1%). Additionally, 90.3% of caregivers reported that their feedback was led by the same provider who completed the testing ($n = 242$). Per caregiver report, the feedback was most commonly completed by a clinical psychologist (38.5%) and pediatrician (26.9%). In 83.2% of cases, there was at least one other person present (e.g., child, partner, other professional, or family member) during the feedback session, and in 51.1% of cases, the child receiving the diagnosis was present in the session.

Table 11

Feedback Session Descriptives

Categories	<i>n</i>	%
Feedback Length		
Less than 30 min	82	30.6
31-60 min	145	54.1
61-90 min	38	14.2
91+ min	3	1.1
<i>Total</i>	<i>268</i>	<i>100.0</i>
Others Present at Feedback		
Significant other/partner	99	30.9
Child receiving the diagnosis	137	51.1
Other family members (e.g., grandparents)	83	31.0

Other professionals (e.g., teachers)	50	18.7
Nobody else was present	45	16.8
<i>Total</i>	<i>268</i>	<i>100.0</i>
Clinician Completing Feedback		
Clinical Psychologist	10	38.5
School Psychologist/Diagnostician	2	7.7
Psychiatrist	2	7.7
Pediatrician	7	26.9
Family Medicine Physician	1	3.8
Neurologist	3	11.5
Psychology/Medical Student	1	3.8
<i>Total</i>	<i>26</i>	<i>100.0</i>

Furthermore, we investigated what elements were included in the feedback session. The recurrent findings indicated that in 66.4% of feedback sessions, caregivers were provided with a written report, 79.1% were provided with a list of final diagnoses, and in 62.3% of cases, the provider shared recommendations and future plans with the caregivers. Only about half of the caregivers reported being familiarized with the content of the report (53.0%), measures used (50.4%), and psychometrics (47.4%). 59.0% of caregivers were provided with information about ASD, and 40.8% of caregivers looked up additional resources/information after the session. Interestingly, only 24.3% of caregivers reported that they were provided with time to think and process their emotions during the feedback session, and 15.7% of caregivers reported being referred to another professional.

Caregivers were further asked if they experienced any barriers when following through with the provided recommendations. While 32.8% of caregivers did not report any factors that would hinder their recommendation follow through, the most commonly endorsed barrier was lack of finances (30.6%) followed by lack of available services in the area (25.4%) and lack of time (22.4%). Notably, 20.1% of caregivers reported feeling that they did not have sufficient knowledge of the recommended services, 9.3% of caregivers were unable to find services in their

preferred language, and 4.5% of caregivers struggled to access services due to fear or shame. 13.1% of caregivers cited some other factor that hindered their ability to follow through, among which the most commonly cited were the length of the waitlist for treatment services, distrust in Applied Behavior Analysis (ABA) therapy, lack of fit between the recommended services and the child's age, the discrepancy between the family values/needs and the recommended services, inability to obtain the recommended supports from school (e.g., Individualized Education Program or 504 plan), difficulties with insurance coverage, and changes related to Covid-19 pandemic.

Table 12

Feedback Session Process

Categories	<i>n</i>	%
Elements Included in Feedback		
Familiarized with the structure/purpose	129	48.1
Provided with written report	178	66.4
Familiarized with the content of the report	142	53.0
Familiarized with the measures used	135	50.4
Familiarized with the psychometrics	127	47.4
Provided with the list of final diagnoses	212	79.1
Provided with information about ASD	158	59.0
Provided with time to think/process emotions	65	24.3
Provided with recommendations/future plan	167	62.3
Provided with additional resources	104	38.8
Referred to another professional	42	15.7
Provided with medication prescription	28	10.4
Scheduled a follow up session	59	22.0
Searched for additional resources after the session	109	40.7
<i>Total</i>	<i>268</i>	<i>100.0</i>
What Hindered Recommendation Follow Through		
Nothing	88	32.8
Lack of finances	82	30.6
Lack of time	60	22.4
Services not available at the location	68	25.4
Services not available in preferred language	25	9.3
Fear/shame	12	4.5
Lack of knowledge of the recommended services	54	20.1
Other	35	13.1

<i>Total</i>	<i>268</i>	<i>100.0</i>
--------------	------------	--------------

The current study further investigated what provider characteristics were perceived as helpful or unhelpful by the caregivers during the feedback session. Caregivers were able to rate each characteristic as either helpful, unhelpful, did not show, or do not recall. Overall, the most helpful provider characteristics were careful listening (82.5%), being understanding (81.0%), maintaining eye contact (76.5%), showing compassion (75.0%), being hopeful (72.4%), and being realistic (71.3%). The most unhelpful provider characteristics per caregiver report included pitying the caregiver (18.7%), seeming distracted (15.3%), allowing interruptions (14.6%), and having a tense body posture (14.2%). Lastly, the least frequently exhibited characteristics were provider distractibility (64.2%), pitying of the caregiver and provider anxiety (62.7%), tense body posture (53.4%), and the use of humor (33.6%).

Table 13

Provider Characteristics

Categories	%Helpful	%Unhelpful	%Did not show	%No recall	N
Showed compassion	75.0	9.0	11.6	4.5	268
Was realistic	71.3	13.1	11.6	4.1	268
Maintained eye-contact	76.5	6.7	6.7	10.1	268
Had tense body posture	20.5	14.2	53.4	11.9	268
Listened carefully	82.5	7.1	8.6	1.9	268
Used humor	40.3	11.6	33.6	14.6	268
Allowed interruptions	62.7	14.6	13.1	9.7	267
Was understanding	81.0	8.6	7.1	3.0	267
Was hopeful	72.4	8.6	12.3	6.7	268
Seemed anxious	17.5	10.8	62.7	9.0	268
Pitied me	11.2	18.7	62.7	7.5	268
Seemed distracted	13.1	15.3	64.2	7.1	267

The current study also asked the caregivers to identify all emotions that they experienced during the feedback. The most commonly endorsed emotion was sadness (51.9%), followed by

anxiety (44.8%), acceptance (44.0%), relief (42.5%), overwhelmed (38.4%), and powerlessness (31.0%). Only 7.8% of caregivers reported feeling doubtful and 8.6% reported feeling ashamed. Among other cited emotions belonged feelings of gratefulness, excitement, validation, and happiness. Some caregivers also reported feeling offended, broken, surprised, irritated and prepared.

Table 14

Caregiver Emotions During Feedback

Categories	<i>n</i>	%
Sad	139	51.9
Anxious	120	44.8
Accepting	118	44.0
Relieved	114	42.5
Overwhelmed	103	38.4
Powerless	83	31.0
Guilty	71	26.5
Optimistic	67	25.0
Confused	59	22.0
Shocked	49	18.3
Empowered	42	15.7
Devastated	41	15.3
Lonely	40	14.9
Angry	31	11.6
Ashamed	23	8.6
Doubtful	21	7.8
Other	16	6.0
<i>Total</i>	<i>268</i>	<i>100</i>

Finally, caregivers were asked to rate their experiences following the feedback session on a scale from 0-100 (0 = Not at all; 100 = A great deal). When asked to what extent receiving the ASD diagnosis changed their perception of the child, most caregivers' answers fell between the “a little” to “a moderate amount” categories ($M = 34.62$, $SD = 33.23$, $N = 268$). When asked about the degree to which their expectations of the child changed after receiving the ASD

diagnosis, most caregivers' answers fell in the "a moderate amount" category ($M = 52.63$, $SD = 29.79$, $N = 266$). Most caregivers further rated their family's ($M = 58.25$, $SD = 27.44$, $N = 265$) and friends' ($M = 60.74$, $SD = 23.95$, $N = 264$) immediate response to the child's ASD diagnosis as "neutral" to "somewhat positive." Similarly, most caregivers rated the degree of support within their community after receiving the child's ASD diagnosis as "a moderate amount" to "a lot" ($M = 62.64$, $SD = 24.71$, $N = 264$). Lastly, most caregivers reported perceiving the child's ASD diagnosis as moderately socially stigmatizing ($M = 49.10$, $SD = 30.08$, $N = 262$).

Discussion

The main goal of the current study was to investigate factors that may contribute to caregiver satisfaction with ASD feedback sessions. While previous research on this topic is limited, especially when considering more recent literature specific to the United States, some studies suggested that caregivers often describe the ASD assessment and feedback process as distressing (Farrugia, 2009; Midence & O'Neill, 1999; Ooi, et al., 2016; Whaley, 2007) and unsatisfactory (Brogan & Knussen, 2003; Chamak et al., 2011; Howlin & Moore, 1997; Keenan et al., 2010). Chamak et al. (2011), nonetheless, reported that caregiver dissatisfaction with the feedback process has decreased from 93% in 1960–1989 cohort to 63% in 1990–2005 cohort, suggesting that there may be certain factors that contribute to improved outcomes. The current study thus attempted to examine some of these factors, building on the previous research specific to the provision of ASD feedback (i.e., Mansell & Morris, 2004; Osborne & Reed, 2008; Whaley, 2007) as well as Austin et al.'s (2012) provider manual that discusses best practices when delivering feedback to families of individuals diagnosed with ASD. In addition to the multiple regression model that was used to assess how these factors relate to feedback satisfaction, non-parametric Spearman's Correlation was completed due to concerns regarding

the distribution of some of the variables. Notably, the Spearman's Rank supported the findings of multiple regression whose results are discussed below.

Firstly, it should be highlighted that, compared to the past literature, the results of the current study revealed overall higher level of caregiver feedback satisfaction. Specifically, the mean feedback satisfaction score for the current sample was 71.08 ($SD = 22.33$) on a 0-100 scale. In contrast, Whaley (2007) showed an average feedback satisfaction rating of 3 on a 5-point scale, Howlin & Moore (1997) showed that only 35% of caregivers reported being "very" or "quite" satisfied, and Brogan and Knussen (2003) found that 55% of participants were satisfied with the disclosure of ASD diagnosis during the feedback. Even though no clear conclusions can be drawn at this point, it can be speculated that the observed increase in satisfaction could be contributable to differences in measurement method (e.g., use of online survey, CSQ-3 adapted questions) as well as changes in the field over time (e.g., updated ASD diagnostic criteria, differences in approach to client-provider relationship, development of ASD assessment guidelines, etc.).

Secondly, while not directly related to the proposed hypotheses, it should be mentioned that none of the predicted covariate variables was significantly related to feedback satisfaction. Specifically, the discovery that the child's age and gender identity do not factor into feedback satisfaction should be interpreted as encouraging given that obtaining the ASD diagnosis may be more challenging for females (Eckerd, 2020) and older children (Daniels & Mandell, 2014). Relatedly, considering previous findings that individuals belonging to racial and ethnic minorities as well as those from rural and underserved communities are more likely to experience difficulties accessing ASD evaluation services (Hutton & Caron, 2005; Jo et al., 2015; Martinez et al., 2018; Zuckerman et al., 2014), we were interested to see whether these

family characteristics could also relate to caregiver satisfaction with the feedback process. The results of the current study did not support such prediction, revealing that caregiver racial/ethnic minority status and location within Health Professional Shortage Area (HPSA) were not associated with lower feedback satisfaction. Therefore, while these factors may negatively impact the family's access to adequate health care, they may not necessarily have the same degree of impact on caregivers' experiences and satisfaction with the ASD feedback session.

Furthermore, we were interested to see whether certain caregiver experiences during the ASD evaluation process could influence their satisfaction with the feedback. Building on the research of Howlin & Moore (1997) who suggested that delays in receiving the diagnosis were associated with family dissatisfaction, a prediction regarding the relationship between waitlist length and feedback satisfaction was made. Consistent with the past literature, the current findings revealed that a longer waitlist time was associated with lower feedback satisfaction. Such finding is important as providers of ASD evaluations across the United States report struggling with their ability to serve their clients in a timely fashion (Kanne & Bishop, 2021). Therefore, the knowledge that the waitlist is related to feedback satisfaction may help to further motivate the efforts to decrease the time gap between the caregiver's initial concerns and the provision of the diagnosis and to develop measures that could prevent the decline in caregiver satisfaction due to this factor (e.g., increased transparency and communication with clients about waitlist times).

Additionally, we hypothesized that the usage of caregiver report measures during the assessment could be positively related to caregiver satisfaction as it may help the caregivers to feel more included and heard by the providers. Such a prediction was not supported by the current results, suggesting that the usage of caregiver report measures does not directly translate

to feedback satisfaction. Furthermore, per recommendations made by Austin et al. (2012) to schedule enough time for the feedback to allow for discussion and processing and to open the feedback session to other individuals who can provide support for the family while recognizing that the presence of small children may be disruptive, we evaluated whether the length of the feedback session and the presence of others is related to feedback satisfaction. Neither one of these variables was found to be a significant predictor for the current sample, suggesting that while those recommendations are logical and likely not harmful, they may not necessarily play an important role from the caregiver's perspective.

Next, inspired by the research of Whaley (2007) who asked caregivers to indicate which characteristics the providers demonstrated during the feedback, we aimed to evaluate what provider characteristics may resonate with the caregivers and impact their satisfaction with the session. Consistent with Whaley (2007) who found that caregivers most commonly identified their provider as realistic, compassionate, open to listening, and understanding, the current sample also rated these characteristics among the most helpful along with maintaining eye contact and being hopeful. Using the list of characteristics, we also developed a provider helpfulness score by subtracting all characteristics the caregivers found unhelpful from those they identified as helpful. This process, however, did not yield predicted findings as the provider helpfulness score was not significantly related to feedback satisfaction. Nonetheless, given the limited research on this topic and a lack of an established way of measuring provider helpfulness, alternative approaches should be considered and evaluated in the future to obtain a better understanding of the possible relationship between this variable and feedback satisfaction.

In addition to provider helpfulness, three other provider characteristics (i.e., advocacy, sensitivity, and the value of caregiver input) were measured on a continuous rating scale ranging

from 0 to 100. Based on the current sample, the mean rating of the perceived caregiver input value was 73.8 ($SD = 23.8$), followed by provider advocacy with 71.7 ($SD = 24.4$) and provider sensitivity with 68.9 ($SD = 27.3$). Nonetheless, only provider advocacy and the value of caregiver input were positively associated with feedback satisfaction. While such finding replicated the results of Whaley (2007) showing a strong correlation between the perceived value of parental input and feedback satisfaction ($r = .59$), the fact that provider sensitivity was not associated with feedback satisfaction brings up a question regarding its importance during feedback. Specifically, Harnett et al. (2009) reported that providers often find it difficult to disclose the diagnosis to parents in a sensitive manner due to a lack of formal training and support. However, since the current results imply that caregivers may not necessarily value the provider's ability to take a sensitive approach when discussing the results as much as they value the provider's advocacy for the child's needs and the ability to listen to the caregiver's opinion and have an open discussion during the feedback session, considerations for future clinical training in this area should be made. Such interpretation is also in concordance with Austin et al. (2012)'s recommendation that providers should use clear and direct language when discussing the diagnosis of ASD and other comorbid diagnoses.

As discussed earlier, previous literature also suggested that caregivers often experience emotional distress when provided with their child's diagnosis (Graungaard & Skov, 2007; Keenan et al., 2010; Whitaker, 2002). Specifically to the provision of ASD diagnosis, Whaley (2007) found that some caregivers reported feeling overwhelmed, anxious, and confused while others described mixed feelings consisting of relief, devastation, and self-blame (Farrugia, 2009; Midence & O'Neill, 1999; Ooi, et al., 2016). The current study replicated these findings, showing that caregivers endorsed experiencing a mix of positive and negative affectivity, with

the top seven being sadness, anxiety, acceptance, relief, overwhelm, powerlessness, and guilt. Nonetheless, to date, no study has investigated the relationship between emotional distress count and valence and caregiver feedback satisfaction. While the emotional distress count was calculated through the addition of individual emotions (e.g., sadness, shame, anxiety), the valence was measured on a continuous rating scale by asking the caregivers to rate how distressing the experience of receiving the child's ASD diagnosis during the feedback was. Surprisingly, the current results revealed that a higher number of endorsed distressing emotions was linked to lower feedback satisfaction but the same did not apply to emotional distress valence.

Given these findings, we argue that providers should expect the caregivers to experience a range of emotions during the feedback process and normalize such experiences for their clients. The findings also suggest that caregivers who experience higher levels of distress (e.g., crying, raising voice) may not necessarily be dissatisfied with the overall feedback process, and providers should thus be comfortable managing these emotions during the session. While this conclusion is consistent with the recommendation of Austin et al. (2012) that providers should give the family time to process the meaning of the diagnosis within the session, it seems to conflict with the current finding that only 24.3% of caregivers felt as if they were provided with time to think and process their emotions during the feedback. While we hypothesize that such discrepancy between the recommendations and the actual practice is likely related to factors such as insurance coverage and large waitlists which may limit the time providers can spend on a feedback session, further investigation is necessary.

Finally, given the limited amount of information about the typical practice among providers within the United States, the current study aimed to investigate some of the ASD

feedback session trends as recalled by the caregivers. While the goal of the current study was to solely describe the caregiver's experiences, future analyses should be conducted to determine whether other factors (e.g., provision of a written report) could relate to feedback satisfaction as many of these in-session elements have been recommended by Austin et al.'s (2012) provider's guide. Aside from the in-session experiences, we were also interested in learning more about recommendation follow-through and the impact of receiving the child's ASD diagnosis. Notably, only about a third of participants reported that they did not experience any barriers when accessing the recommended services for their children, which is consistent with findings of past research suggesting that many families struggle to access evidence-based services due to a variety of reasons (Adams & Young, 2021; Chiri & Warfield, 2012; Lim et al., 2021). Most caregivers also reported experiencing mild to moderate changes in their perceptions and expectations of the child after receiving the ASD diagnosis. The impact of such change on the caregiver-child interaction is unknown for the current sample, but past research suggested that receiving the ASD diagnosis can lead to both positive and negative outcomes depending on whether a parental resolution was achieved (Milshtein, 2010). The ability of the caregiver to adapt to the change and have positive outcomes may also be influenced by the amount of social support the family receives (Ekas et al., 2010). Interestingly, the current study found that while most caregivers further rated their family's and friends' immediate response to the child's ASD diagnosis as neutral to somewhat positive, they rated the degree of support from their community as moderate to large. Nonetheless, consistently with the findings that stigma related to ASD diagnosis continues to be prevalent in US communities and can negatively impact the families, most caregivers in the current study also reported perceiving the child's ASD diagnosis as moderately socially stigmatizing.

Implications and Limitations

The present study expanded on the available literature investigating caregiver experiences with the ASD feedback process. In addition to the four factors related to feedback satisfaction that were identified and discussed, the current study also described some of the shared trends in feedback delivery among US providers as reported by the caregivers. By engaging in this type of research, we hoped to not only shed more light on the process of ASD feedback but also develop a basis for evidence-based practice when delivering ASD diagnosis to caregivers. Recognizing factors associated with higher caregiver satisfaction may provide the field with more knowledge regarding clients' wants and needs and inform professional guidelines for feedback delivery. We argue that doing so is important given that past studies have also found an association between effective feedback and greater treatment involvement (Boyd & Corley, 2001; Brogan & Knussen, 2003; Keenan et al., 2010).

It should, nonetheless, be noted that the current study has several limitations. First, while there was not a significant relationship between time since diagnosis and feedback satisfaction, suggesting that there likely was not a recall effect among the participating caregivers that would be influencing their satisfaction score, the current study is built on retrospective data, at times collected several years following the feedback session. Although we attempted to minimize the effect of the time delay by encouraging caregivers to refer back to the report and materials provided during the feedback session and by the inclusion of statements such as "to the best of your recollection" within the survey, the current study design may limit the accuracy of the reported data, especially in areas such as the recall of provider characteristics and emotions experienced during the session. Future studies on this topic should, therefore, consider increasing the immediacy of the data collection following the feedback session.

Another limitation of the current study is related to its sole reliance on the caregiver's report. Though we were primarily interested in exploring caregiver experiences, the inclusion of other reports (e.g., child's, provider's) would allow for comparison of different perspectives. The accuracy of caregiver report in certain areas (e.g., the inclusion of specific measures during the assessment process, inclusion of certain feedback elements during the feedback session) may also be impacted by the caregiver's lack of insight in the ASD evaluation and feedback process. As the current study and past literature also indicated, caregivers often experience distressing emotions during the feedback, which may, in turn, impact their recall of specific details from the feedback session (e.g., discussion of the child's strength, provider characteristics, etc.). Future research should thus focus on investigating and contrasting perspectives from multiple respondents.

Furthermore, concerning Hypothesis 1 and 2, the results may have been affected by the limited number of participants in the individual categories (i.e., ethnic/racial identity and HPSA status), which resulted in the need to take a dichotomous approach to both the mentioned variables. Doing so, unfortunately, limited our ability to evaluate possible differences between the racial and ethnic groups as well as the degree of provider shortage within the participant's area. Similarly, in regard to the predicted covariate variables, most of the respondents identified as female and biological mothers, and most of the children diagnosed with ASD were identified as male. While these caregiver and child characteristics are not unexpected given that women and biological mothers are more likely to be primary caregivers (Laughlin, 2013) and males are more likely to receive the ASD diagnosis than females with a ratio of 3:1 (Loomes et al., 2017), obtaining data from less frequently represented groups is important for the investigation of possible discrepancies in care quality and satisfaction.

Lastly, the present study employed a correlational design and investigated only a limited number of factors that may be associated with feedback satisfaction, restricting the number of inferences that can be made from the current results. Nonetheless, we recognize that with a larger number of studies done on this topic, more complex models may be developed. As previously discussed, there currently also are not any established ways of measuring ASD feedback satisfaction and other factors (e.g., provider helpfulness, in-session level of emotional distress), for which further investigation of this topic is warranted. This study further failed to collect data about the method of ASD assessment and feedback delivery (i.e., virtual vs. in-person session). Given that the use of telehealth services within the United States has drastically increased in the recent years following the onset of the coronavirus disease 2019 (COVID-19) pandemic (Li et al., 2022), consideration of its impact on caregiver feedback satisfaction appears pivotal to future research. Caregiver preparedness for receiving the child's ASD diagnosis was also not assessed by the current study as this concept has only recently started being investigated (Anderberg & South, 2021). Nonetheless, consistently with the recommendation that feedback should be happening during the course of the evaluation rather than rather and a single session (Austin et al., 2012), future work in the field should focus on expanding to factors occurring before and throughout the ASD diagnostic process.

References

- Achenbach, T. M. (1999). *The Child Behavior Checklist and related instruments*. In M. E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcomes assessment* (pp. 429–466). Lawrence Erlbaum Associates Publishers.
- Adams, D., & Young, K. A. (2021). Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*, 8, 436–453 <https://doi.org/10.1007/s40489-020-00226-7>
- Aiello, R., Ruble, L., & Esler, A. (2017). National Study of School Psychologists' Use of Evidence-Based Assessment in Autism Spectrum Disorder. *Journal of Applied School Psychology*, 33(1), 67-88, <https://doi.org/10.1080/15377903.2016.1236307>
- Allen, R. A., Robins, D. L., & Decker, S. L. (2008). Autism spectrum disorders: Neurobiology and current assessment practices. *Psychology in the Schools*, 45, 905-917. <https://doi.org/10.1002/pits.20341>
- American Psychiatric Association (2022). *Diagnostic and statistical manual of mental disorders (5th ed.) Text Revision*. American Psychiatric Publishing.
- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. American Psychiatric Publishing.
- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders (3rd ed.)*. Author.
- Anderberg, E., & South, M. (2021). Predicting Parent Reactions at Diagnostic Disclosure Sessions for Autism. *Journal of Autism and Developmental Disorders*, 51, 3533–3546 <https://doi.org/10.1007/s10803-020-04817-5>

- Antezana, L., Scarpa, A., Valdespino, A., Albright, J., & Richey, J. A. (2017). Rural trends in diagnosis and services for autism spectrum disorder. *Frontiers in Psychology*, 8. <https://doi.org/10.3389/fpsyg.2017.00590>
- Austin, H., Katz, T., Paul, J., & Reyes, J. P. (2012, September) *A clinician's guide to providing effective feedback to families affected by autism*. http://aspergers.ca/wp-content/uploads/media-library/article/pdfs/a_clinicians_guide_to_delivering_feedback_manual.pdf
- Bavin, E. L., Kidd, E., Prendergast, L., Baker, E., Dissanayake, C., & Prior, M. (2014). Severity of autism and language processing. *Autism Research*, 7, 687-694. <https://doi.org/10.1002/aur.1410>
- Boyd, R. D., & Corley, M. J. (2001). Outcome survey of early intensive behavioral intervention for young children with autism in a community setting. *Autism*, 5(4), 430–441. <https://doi.org/10.1177/1362361301005004007>
- Brogan, C. A., & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder. *Autism*, 7(1), 31-46. <https://doi.org/10.1177/1362361303007001004>
- Chiri, G., & Warfield, M. E. (2012). Unmet Need and Problems Accessing Core Health Care Services for Children with Autism Spectrum Disorder. *Maternal and Child Health Journal*, 16, 1081–1091. <https://doi.org/10.1007/s10995-011-0833-6>
- Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences (2nd ed.)*. Lawrence Erlbaum Associates.
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2015). *Applied multiple regression/correlation analysis for the behavioral sciences*. Lawrence Erlbaum Associates.

- Constantino, J. N., & Gruber, C. P. (2012). *Social Responsiveness Scale, Second Edition (SRS-2)*. Western Psychological Services.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2015). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153-162. <https://doi.org/10.1177/1362361315573636>
- Daniels, A. M., & Mandell, D. S. (2014). Explaining differences in age at autism spectrum disorder diagnosis: A critical review. *Autism, 18*(5), 583–597. <https://doi.org/10.1177/1362361313480277>
- Eckerd, M. (2020). Detection and diagnosis of ASD in females. *Journal of Health Service Psychology, 46*(1), 37–47. <https://doi.org/10.1007/s42843-020-00006-1>
- Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 40*, 1274–1284. <https://doi.org/10.1007/s10803-010-0986-y>
- Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. *History of The Human Sciences, 26*(3), 3-31. <https://doi.org/10.1177/0952695113484320>
- Farrugia, D. (2009), Exploring stigma: medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness, 31*. 1011-1027. <https://doi.org/10.1111/j.1467-9566.2009.01174.x>
- Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191.

- Filipek, P. A., Accardo, P. J., Baranek, G. T., Cook, E. H., Jr., Dawson, G., Gordon, B. Gravel, j. S., Johnson, C. P., Kallen, R. J., Levy, S. E., Minshew, N. J., Ozonoff, S., Prizant, B. M., Rapin, I., Rogers, S. J., Stone, W. L., Teplin, S., Tuchman, R. F., & Volkmar, F. R. (1999). The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 29, 439–484. <https://doi.org/10.1023/a:1021943802493>
- Gaspar De Alba, M. J., & Bodfish, J. W. (2011). Addressing parental concerns at the initial diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, 5(1), 633-639. <https://doi.org/10.1016/j.rasd.2010.07.009>
- Ghasemi, A., & Zahediasl, S. (2012). Normality tests for statistical analysis: A guide for non-statisticians. *International Journal of Endocrinology and Metabolism*, 10(2), 486–489. doi:10.5812/ijem.3505
- Goldstein, S., & Ozonoff, S. (2018). *Assessment of Autism Spectrum Disorder, Second Edition*. Guilford Press.
- Graungaard, A. H., & Skov, L. (2007). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health and Development*, 33(3), 296-307. <https://doi.org/10.1111/j.1365-2214.2006.00666.x>
- Harnett, A., Tierney, E., & Guerin, S. (2009). Convention of hope-communicating positive, realistic messages to families at the time of a child's diagnosis with disabilities. *British Journal of Learning Disabilities*, 37(4), 257-264. <https://doi.org/10.1111/j.1468-3156.2009.00580.x>
- Hartley, D. (2004). Rural health disparities, population health, and rural culture. *American Journal of Public Health*, 94, 1675–1678. <https://doi.org/10.2105/ajph.94.10.1675>

Health Professional Shortage Areas. (2020, May). Bureau of Health Workforce. Retrieved July 16, 2020, from <https://bhw.hrsa.gov/shortage-designation/hpsas>

HPSA Find. (n.d.) Health Resources and Services Administration. Retrieved July 16, 2020, from <https://data.hrsa.gov/tools/shortage-area/hpsa-find>

Hidalgo, N. J., McIntyre, L. L., & McWhirter, E. H. (2015). Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual & Developmental Disability*, 40(2), 147–155.
<https://doi.org/10.3109/13668250.2014.994171>

Howlin, P. & Moore, A. (1997) Diagnosis in Autism: A survey of over 1200 patients in the UK, *Autism*, 1(2). 135–62. <https://doi.org/10.1177/1362361397012003>

Huerta, M., & Lord, C. (2012). Diagnostic evaluation of autism spectrum disorders. *Pediatric clinics of North America*, 59(1). <https://doi.org/10.1016/j.pcl.2011.10.018>

IBM Corporation (2017). *IBM SPSS Statistics for Windows* (Version 25.0). IBM Corporation.
<https://www.ibm.com/analytics/spss-statistics-software>

Jo, H., Schieve, L. A., Rice, C. E., Yeargin-Allsopp, M., Tian, L. H., Blumberg, S. J., Boyle, C. A. (2015). Age at autism spectrum disorder (ASD) diagnosis by race, ethnicity, and primary household language among children with special health care needs. *Maternal and Child Health Journal*, 19(8), 1687–1697. <https://doi.org/10.1007/s10995-015-1683-4>

Kalkbrenner, A. E., Daniels, J. L., Emch, M., Morrissey, J., Poole, C., & Chen, J. (2011). Geographic access to health services and diagnosis with an autism spectrum disorder. *Annals of Epidemiology*, 21(4), 304-310. <https://doi.org/10.1016/j.annepidem.2010.11.010>

- Kanne, S. M. & Bishop, S. L. (2021), Editorial Perspective: The autism waitlist crisis and remembering what families need. *Journal of Child Psychology and Psychiatry*, 62, 140-142. <https://doi.org/10.1111/jcpp.13254>
- Kanne, S. M., Gerber, A. J., Quirnbach, L. M., Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2010). The role of adaptive behavior in autism spectrum disorders: implications for functional outcome. *Journal of Autism and Developmental Disorders*, 41(8), 1007-1018. <https://doi.org/10.1007/s10803-010-1126-4>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities*, 23(4), 390-397. <https://doi.org/10.1111/j.1468-3148.2010.00555.x>
- Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders*, 46, 942–953. <https://doi.org/10.1007/s10803-015-2637-9>
- Kjellmer, L., Hedvall, Å, Fernell, E., Gillberg, C., & Norrelgen, F. (2012). Language and communication skills in preschool children with autism spectrum disorders: Contribution of cognition, severity of autism symptoms, and adaptive functioning to the variability. *Research in Developmental Disabilities*, 33(1), 172-180. <https://doi.org/10.1016/j.ridd.2011.09.003>

- Krahn, G. L., Eisert, D., & Fifield, B. (1990). Obtaining Parental Perceptions of the Quality of Services for Children with Special Health Needs. *Journal of Pediatric Psychology*, 15(6), 761–774. <https://doi.org/10.1093/jpepsy/15.6.761>
- Laerd Statistics (2015). *Multiple Regression using SPSS Statistics*. Statistical tutorials and software guides. Retrieved July 27, 2020, from <https://statistics.laerd.com/>
- Larsen, D.L., Attkisson, C., Hargreaves, W.A. and Nguyen, T.D. (1979). Assessment of client/patient satisfaction: Development of a general scale. *Evaluation and Program Planning*, 2, 197-207. [https://doi.org/10.1016/0149-7189\(79\)90094-6](https://doi.org/10.1016/0149-7189(79)90094-6)
- Laughlin, L. (2013, April). *Who's Minding the Kids? Child Care Arrangements: Spring 2011*. Washington, DC.; Economics and Statistics Administration.
- Leekam S. (2013) *Diagnostic Interview for Social and Communication Disorders*. In: Volkmar F.R. (eds) *Encyclopedia of Autism Spectrum Disorders*. Springer.
- Li, H., Glecia, A., Kent-Wilkinson, A., Leidl, D., Kleib, M., & Risling, T. (2022). Transition of Mental Health Service Delivery to Telepsychiatry in Response to COVID-19: A Literature Review. *Psychiatric Quarterly*, 93, 181–197. <https://doi.org/10.1007/s11126-021-09926-7>
- Li, P., Stuart, E. A., & Allison, D. B. (2015). Multiple Imputation: A flexible tool for handling missing data. *JAMA*, 314(18), 1966–1967. <https://doi.org/10.1001/jama.2015.15281>
- Lim, N., O'Reilly, M., Sigafos, J., Lancioni, G. E., & Sanchez, N. J. (2021). A Review of Barriers Experienced by Immigrant Parents of Children with Autism when Accessing Services. *Review Journal of Autism and Developmental Disorders*, 8, 366–372. <https://doi.org/10.1007/s40489-020-00216-9>

- Loomes, R., Hull, L., & Mandy, W. P. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), 466–474.
<https://doi.org/10.1016/j.jaac.2017.03.013>
- Lord, C., Rutter, M., DiLavore, P.C., Risi, S., Gotham, K., & Bishop, S. L. (2012). *Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) Manual (Part I): Modules 1-4*. Western Psychological Services.
- Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., Dirienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L., Harrington, R. A., Huston, M., ... Dietz, P. M. (2020). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveillance Summaries*, 69(4), 1–12.
<https://doi.org/10.15585/mmwr.ss6904a1>
- Magiati, I., Tay, X. W., & Howlin, P. (2014). Cognitive, language, social and behavioural outcomes in adults with autism spectrum disorders: A systematic review of longitudinal follow-up studies in adulthood. *Clinical Psychology Review*, 34(1), 73-86.
<https://doi.org/10.1016/j.cpr.2013.11.002>
- Mandell, D. S., Novak, M. M., & Zubritsky, C. D. (2005). Factors associated with age of diagnosis among children with autism spectrum disorders. *Pediatrics*, 116(6), 1480–1486. <https://doi.org/10.1542/peds.2005-0185>

- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism*, 8(4), 387–407. <https://doi.org/10.1177/1362361304045213>
- Martinez, M., Thomas, K. C., Williams, C. S., Christian, R., Crais, E., Pretzel, R., & Hooper, S. R. (2018). family experiences with the diagnosis of autism spectrum disorder: system barriers and facilitators of efficient diagnosis. *Journal of Autism and Developmental Disorders*, 48(7), 2368-2378. <https://doi.org/10.1007/s10803-018-3493-1>
- McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., & Irvine, L. (2015). Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults. *Research in Developmental Disabilities*, 45-46, 300–306. <https://doi.org/10.1016/j.ridd.2015.07.033>
- Merker, B. M., Hanson, W. E., & Poston, J. M. (2010). National Survey of Psychologists' Training and Practice in Breaking Bad News: A Mixed Methods Study of the MUM Effect. *Journal of Clinical Psychology in Medical Settings*, 17(3), 211–219. <https://doi.org/10.1007/s10880-010-9197-0>
- Midence, K., & O'Neill, M. (1999). The experience of parents in the diagnosis of autism. *Autism*, 3(3), 273-285. <https://doi.org/10.1177/1362361399003003005>
- Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., & Levi, S. (2010). Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics. *Journal of Autism and Developmental Disorders*, 40, 89–99. <https://doi.org/10.1007/s10803-009-0837-x>
- Mohamed, F. E., Zaky, E. A., Youssef, A., Elhossiny, R., Zahra, S., Khalaf, R., et al. (2016). Screening of Egyptian toddlers for autism spectrum disorder using an Arabic

- validated version of M-CHAT: Report of a community-based study (Stage I). *European Psychiatry*, 34, 43–48. <https://doi.org/10.1016/j.eurpsy.2016.01.2421>
- Nursey, A. D., Rohde, J. R., & Farmer, R. D. T. (1991). Ways of telling new parents about their child and his or her mental handicap: a comparison of doctors' and parents' views. *Journal of Intellectual Disability Research*, 35(1), 48–57. <https://doi.org/10.1111/j.1365-2788.1991.tb01030.x>
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric disease and treatment*, 12, 745–762. <https://doi.org/10.2147/NDT.S100634>
- Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism*, 12(3), 309-324. <https://doi.org/10.1177/1362361307089517>
- Ozonoff, S. , Goodlin-Jones, B. L., & Solomon, M. (2005). Evidence-based assessment of autism spectrum disorders in children and adolescents. *Journal of Clinical Child and Adolescent Psychology*, 34(3), 523-540. https://doi.org/10.1207/s15374424jccp3403_8
- Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., Managhan, T., Reitzel , J., & Williams, J. (2011). Predictors of outcome for children receiving intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, 5(1), 592–603. <https://doi.org/10.1016/j.rasd.2010.07.003>
- Quine L. & Pahl J. (1986) First diagnosis of severe mental handicap: characteristics of unsatisfactory encounters between doctors and parents. *Social Science & Medicine*, 22, 53-62. [https://doi.org/10.1016/0277-9536\(86\)90308-4](https://doi.org/10.1016/0277-9536(86)90308-4)

Quine L. & Pahl J. (1987) First diagnosis of severe handicap: a study of parental reactions.

Developmental Medicine and Child Neurology 29, 232-42.

<https://doi.org/10.1111/j.1469-8749.1987.tb02141.x>.

Reynolds, C.R., & Kamphaus, R.W. (2015). *Behavior assessment for children: Third edition.*

(BASC-3). Pearson.

Rhoades, R. A., Scarpa, A., & Salley, B. (2007). The importance of physician knowledge of autism spectrum disorder: Results of a parent survey. *BMC Pediatrics*, 7(1).

<https://doi.org/10.1186/1471-2431-7-37>

McGrath, R. E. (2001). Toward more clinically relevant assessment research. *Journal of Personality Assessment*, 77(2), 307-332. https://doi.org/10.1207/S15327752JPA7702_12

Robins, D. L., Fein, D., & Barton, M. (2009). *Modified Checklist for Autism in Toddlers, Revised, with Follow-up (M-CHAT-R/F)*. Self-published.

Rutter, M., Bailey, A., & Lord, C. (2003). *The Social Communication Questionnaire*. Western Psychological Services.

Rutter, M., Le Couteur, A., & Lord, C. (2003b). *Autism Diagnostic Interview – Revised, Manual*. Western Psychological Services.

Schopler, E., Van Bourgondien, M. E., Wellman, G. J., & Love, S. R. (2010). *Childhood Autism Rating Scale – 2nd Edition*. Western Psychological Services.

Skellern, C., McDowell, M., & Schluter, P. (2005). Diagnosis of autistic spectrum disorders in Queensland: Variations in practice. *Journal of Paediatrics and Child Health*, 41, 413-8.

<https://doi.org/10.1111/j.1440-1754.2005.00667.x>.

Smith-Young, J., Chafe, R., & Audas, R. (2020). “Managing the Wait”: Parents’ Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed

With Autism Spectrum Disorder. *Health Services Insights*, 13.

<https://doi.org/10.1177/1178632920902141>

Steiner, A. M., Goldsmith, T. R., Snow, A. V., & Chawarska, K. (2012) Practitioner's guide to assessment of autism spectrum disorders in infants and toddlers. *Journal of Autism and Developmental Disorders*, 42(6), 1183-1196. <https://doi.org/10.1007/s10803-011-1376-9>

Streeter, R. A., Snyder, J. E., Kepley, H., Stahl, A. L., Li, T., & Washko, M. M. (2020). The geographic alignment of primary care Health Professional Shortage Areas with markers for social determinants of health. *Plos One*, 15(4).

<https://doi.org/10.1371/journal.pone.0231443>

Hyman, S. L., Levy, S. E., & Myers, S. M. (2020) Council on children with disabilities: Section on developmental and behavioral pediatrics.

Pediatrics, 145(1). <https://doi.org/10.1542/peds.2019-3447>

Thurm, A., Manwaring, S. S., Swineford, L., & Farmer, C. (2015). Longitudinal study of symptom severity and language in minimally verbal children with autism. *Journal of Child Psychology and Psychiatry*, 56, 97-104. <https://doi.org/10.1111/jcpp.12285>

Verhoeven, K. J., Simonsen, K. L., & McIntyre, L. M. (2005). Implementing false discovery rate control: Increasing your power. *Oikos*, 108, 643-647. <https://doi.org/10.1111/j.0030-1299.2005.13727.x>

Ward, S. L., Sullivan, K. A., & Gilmore, L. (2016). Practitioner Perceptions of the Assessment and Diagnosis of Autism in Australia. *Australian Psychologist*, 51(4), 272-279.

<https://doi.org/10.1111/ap.12211>

Whaley, J. (2007). *Diagnosis of an autism spectrum disorder: Parents' perceptions of the interpretive conference*. [Master's Thesis, Miami University]. OhioLink.

- Whitaker, P. (2002). Supporting families of preschool children with autism. *Autism*, 6(4), 411-426. <https://doi.org/10.1177/1362361302006004007>
- Woods, J. J., & Wetherby, A. M. (2003). Early Identification of and Intervention for Infants and Toddlers Who Are at Risk for Autism Spectrum Disorder. *Language, Speech, and Hearing Services in Schools*, 34(3), 180-193. [https://doi.org/10.1044/0161-1461\(2003/015\)](https://doi.org/10.1044/0161-1461(2003/015))
- Zuckerman, K. E., Sinche, B., Mejia, A., Cobian, M., Becker, T., & Nicolaidis, C. (2014). Latino parents' perspectives on barriers to autism diagnosis. *Academic Pediatrics*, 14(3), 301-308. <https://doi.org/10.1016/j.acap.2013.12.004>

Appendix 1

Q1.1 Before you proceed to the survey, please complete the CAPTCHA below.

Q1.2 Informed Consent to Participate Dear Caregiver: We are conducting a research study designed to evaluate experiences and satisfaction with the autism diagnostic process. As a caregiver of a child who was diagnosed with autism spectrum disorder (ASD)/Asperger's syndrome before the age of 18, you are invited to complete a web-based questionnaire regarding your experience with the evaluation process of your child. This survey is expected to take approximately 15-20 minutes to complete. You will be asked questions regarding your demographic information, the evaluation process (e.g., how the testing was completed), and the feedback process (i.e., how you were informed about the diagnosis). We appreciate your time and responses, as these will give us a better understanding of caregiver's experiences and satisfaction with the autism diagnostic process.

PARTICIPATION: Your participation in this survey is completely voluntary and anonymous. You may refuse to take part in the research or exit the survey at any time without penalty. You are free to decline to answer any particular question you do not wish to answer for any reason.

BENEFITS: Upon completion of the survey, you may enter a drawing for a \$50 Amazon gift card (odds of winning are 1 in 25). **RISKS:** The possible risks or discomforts of the study are minimal. Some participants may feel distressed when answering questions about their child.

CONFIDENTIALITY: Your answers will be collected using Qualtrics, where data will be stored in a password-protected electronic format. Qualtrics does not collect identifying information such as your name or email address (except where discussed above), and therefore, your responses will remain anonymous. No one will be able to identify you or your answers, and no one will know whether or not you participated in the study. Results from this study may be presented at professional meetings or published in professional publications. However, responses are anonymous and reported in a group format.

CONTACT:

If you have questions at any time about the study or the procedures, you may contact Dr. Robert Rieske at riesrobe@isu.edu or via phone at 208-282-4192.

If you feel you have not been treated according to the descriptions in this form, that your rights as a research participant have not been honored during the course of this project, or you have any questions, concerns, or complaints that you wish to address with someone other than the investigator, you may contact the ISU Human Subjects Committee at humsbj@isu.edu or by calling (208) 393-2179.

ELECTRONIC CONSENT: Please select your choice below. You may print a copy of this consent form for your records. Clicking on the "Agree" button indicates that You have read the above information

- You voluntarily agree to participate
- You are 18 years of age or older
- You are a caregiver of at least one child that was diagnosed with autism spectrum disorder (ASD) or Asperger's syndrome prior to age of 18 years
- You have been present at/part of the autism evaluation process
- You are fluent in written English
- You are located in the United States of America or US territories

☐ Agree

☐ Disagree

Q1.3 Are you 18 years of age or older?

☐ Yes

☐ No

Q1.4 Are you fluent in written English?

☐ Yes

☐ No

Q1.5 Are you a caregiver of a child who was diagnosed with Autism/Asperger's syndrome/ASD?

☐ Yes

☐ No

Q1.6

If you are a caregiver of more than one child that was diagnosed with autism/Asperger's syndrome/ASD, please answer the following questions thinking about your 1st experience with autism evaluation.

Q1.7 Were you present at/part of the diagnostic evaluation process? (This may include but is not limited to some of the following activities: bringing child for the evaluation, communicating with the clinician, observing the testing, completing questionnaires, receiving the child's diagnosis, reading the evaluation report.)

☐ Yes

☐ No

Q1.8 Was the child's diagnostic evaluation completed within the United States or US territories?

- ☐ Yes
- ☐ No

Q1.9 What year was the diagnostic evaluation completed?

Q1.10 How old was the child at the time of receiving the autism diagnosis? (in years)

Q1.11 What is your child's gender?

- ☐ Male
- ☐ Female
- ☐ Other, please specify: _____

Q1.12 What is your child's race? (Check all that apply)

- ☐ White/Caucasian
- ☐ Black or African-American
- ☐ Native American or Alaska Native
- ☐ Asian
- ☐ Hawaiian Native or other Pacific Islander
- ☐ Other, please specify: _____

Q1.13 What is your child's ethnicity?

- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino
- ☐ Other, please specify: _____

Q1.14 What is your relationship to your child

- ☐ Biological Mother
- ☐ Biological Father
- ☐ Adoptive/Foster Mother

- ☐ Adoptive/Foster Father
- ☐ Stepmother
- ☐ Stepfather
- ☐ Other, please specify: _____

Q1.15 What is your gender?

- ☐ Male
- ☐ Female
- ☐ Other, please specify: _____

Q1.16 Which race(s) do you identify with? (Check all that apply)

- ☐ White/Caucasian
- ☐ Black or African-American
- ☐ Native American or Alaska Native
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ Other, please specify: _____

Q1.17 Which ethnicity do you most identify with?

- ☐ Hispanic or Latino
- ☐ Not Hispanic or Latino
- ☐ Other, please specify: _____

Q1.19

For the following questions, think back to the time in which you received your child's diagnosis.

Q1.20 How old were you **at the time of receiving your child's diagnosis?**

Q1.21 What was the highest degree or level of education you had completed **at the time of receiving your child's diagnosis?**

- ☐ Less than high school
- ☐ High school graduate
- ☐ Some college
- ☐ 2-year degree
- ☐ 4-year degree
- ☐ Professional degree (e.g., D.C.; M.D.; D.M.A.; D.V.M.; Pharm.D.)
- ☐ Doctorate (e.g., PhD)

Q1.22 What was your total household income before taxes **at the time of receiving your child's diagnosis?**

- ☐ Less than \$25,000
- ☐ \$25,000 to \$34,999
- ☐ \$35,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 to \$149,999
- ☐ \$150,000 or more

Q1.23 How often were finances a stressor for you **at the time of receiving your child's diagnosis?**

- ☐ Never
- ☐ Sometimes
- ☐ About half the time
- ☐ Most of the time
- ☐ Always

Q1.24 Including yourself and all children, how many people lived in your household **at the time of receiving your child's diagnosis?**

Q1.25 What was your home ZIP code **at the time of receiving your child's diagnosis?**

Q2.8 From the time you first contacted the clinician, how many months did you have to wait for the evaluation?

Q3.8

Now, we will be asking you about the testing portion of your evaluation. This may include an interview with you or your child, filling out rating forms about your child, testing of your child, etc. This does not include the "Feedback Session" in which you received your child's diagnosis after testing. We will ask questions about the "Feedback Session" later.

Q3.9 Which of the following elements were included in the testing of your child? (select all that apply)

- ☐ Interview with caregiver(s) and/or the child
 - ☐ Interview with someone else (e.g., teachers, other professionals, other family members)
 - ☐ Caregiver rating scales/Caregiver questionnaires (e.g., MCHAT, ASRS, GARS)
 - ☐ Clinical observation of child (e.g., ADOS, CARS, clinician playing with the child)
 - ☐ Cognitive (IQ/intelligence)/Adaptive measures (e.g., WISC, Bayley, ABAS, Vineland)
 - ☐ Academic achievement (school performance) measures (e.g., Woodcock Johnson)
 - ☐ Other (e.g., speech, medical, sleep, motor, sensory)
-

Q4.1

Now, we would like to ask you questions about the "Feedback Session." A Feedback Session is a session at the end of the testing process when the clinician meets with the caregiver/family to discuss the results and provide the diagnosis.

Q4.2 How long did the feedback session last? (to the best of your recollection)

- ☐ Less than 30 minutes
- ☐ 31-60 minutes
- ☐ 61-90 minutes
- ☐ 91+ minutes
- ☐ I did not have a feedback session

Q4.4 Please, select other individuals present during the feedback session. (select all that apply)

- ☐ Significant other/partner
- ☐ The child receiving the diagnosis
- ☐ Other family members (e.g., siblings, grandparents)
- ☐ Other professionals (e.g., teachers, therapists)
- ☐ Nobody else was present
- ☐ Other: _____

Q4.5 To the best of your recollection, what happened during the feedback session (select all that apply):

- ☐ I was informed about the structure and purpose of the feedback session
- ☐ I was given a written report
- ☐ I was familiarized with the content of the report
- ☐ I was explained what measures were used
- ☐ I was explained the meaning of the scores
- ☐ I was informed what diagnoses my child meets (i.e. Autism Spectrum Disorder, Cognitive Disability, ADHD)
- ☐ I was provided general information about autism
- ☐ I was provided time to think about the diagnoses and process my emotions

- ☐ I was provided with recommendations/future plan (i.e. treatment options)
- ☐ I was provided with additional resources (e.g. booklets, books, websites, parent groups)
- ☐ I was referred to another professional
- ☐ My child was given prescription for medication
- ☐ Follow up session was scheduled
- ☐ I looked up additional resources after the session (e.g., parenting groups, online forums)

Q4.6 Was the clinician who provided you the diagnosis the same as the one who completed the testing?

- ☐ Yes
- ☐ No

Q4.7 Who was the primary clinician that completed the feedback session?

- ☐ Clinical Psychologist
- ☐ School Psychologist
- ☐ Psychiatrist
- ☐ Pediatrician
- ☐ Family Medicine Physician
- ☐ Neurologist
- ☐ Psychology/Medical Student
- ☐ Speech/Language Pathologist
- ☐ Other: _____

Q4.8 Please, rate each of the characteristics that your clinician exhibited during the feedback session (to the best of your recollection).

	Helpful	Unhelpful	Did not exhibit	Do not recall
Showed compassion	☐	☐	☐	☐
Was realistic	☐	☐	☐	☐
Maintained eye-contact	☐	☐	☐	☐
Had tense body posture	☐	☐	☐	☐
Listened carefully	☐	☐	☐	☐
Used humor	☐	☐	☐	☐
Allowed interruptions	☐	☐	☐	☐
Was understanding	☐	☐	☐	☐
Was hopeful	☐	☐	☐	☐
Seemed anxious	☐	☐	☐	☐
Pitied me	☐	☐	☐	☐
Seemed distracted	☐	☐	☐	☐
Other:	☐	☐	☐	☐

Q4.9 The clinician appeared to be advocating for the child's needs during the feedback.

Not at all A little A moderate amount A lot A great deal

0 17 33 50 67 83 100



Q4.10 The clinician valued my input/opinion during the feedback.

Not at all A little A moderate amount A lot A great deal

0 17 33 50 67 83 100



Q4.11 The clinician took a sensitive approach when discussing the child prognosis/future during the feedback.

Not at all A little A moderate amount A lot A great deal

0 17 33 50 67 83 100



Q4.12 If you were to undergo the feedback again, would you return to the same clinician?

Definitely not Probably not Might or might not Probably yes Definitely yes

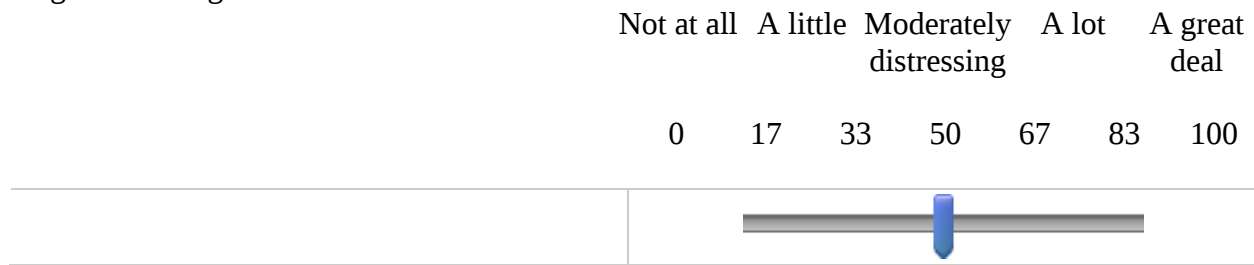
0 17 33 50 67 83 100



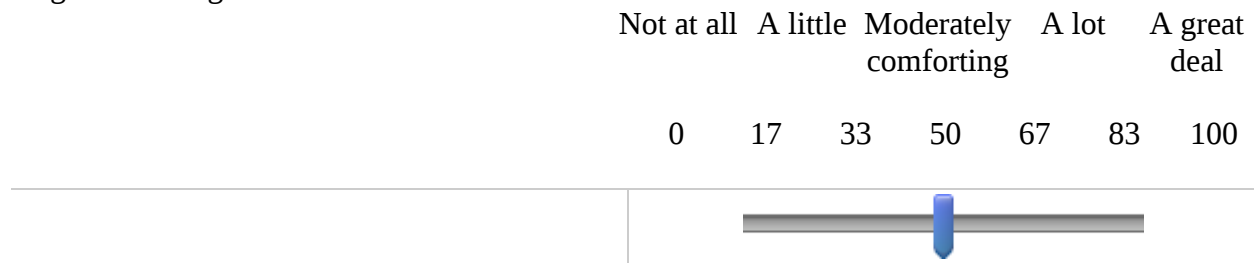
Q4.13 To the best of your recollection, what emotions did you experience after receiving the child's ASD diagnosis during the feedback session? (select all that apply).

- ☐ Sad
- ☐ Guilty
- ☐ Doubtful
- ☐ Anxious
- ☐ Powerless
- ☐ Confused
- ☐ Angry
- ☐ Devastated
- ☐ Overwhelmed
- ☐ Ashamed
- ☐ Shocked
- ☐ Lonely
- ☐ Relieved
- ☐ Empowered
- ☐ Optimistic
- ☐ Accepting
- ☐ Other _____

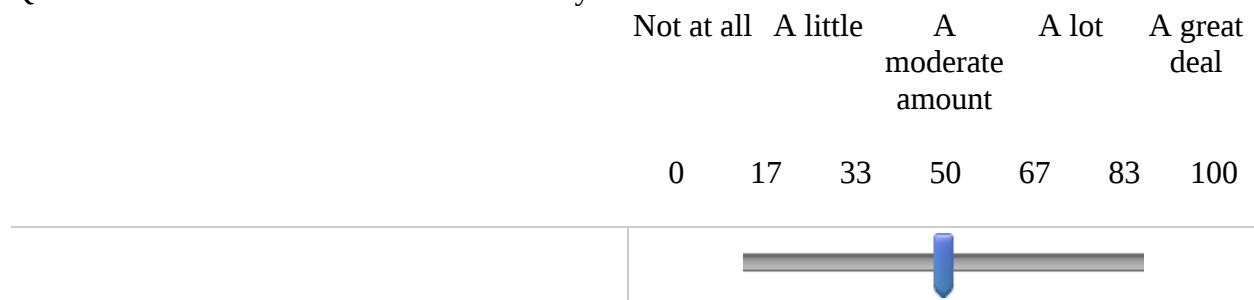
Q4.14 Thinking back, how distressing was the experience of receiving the child's autism diagnosis during the feedback?



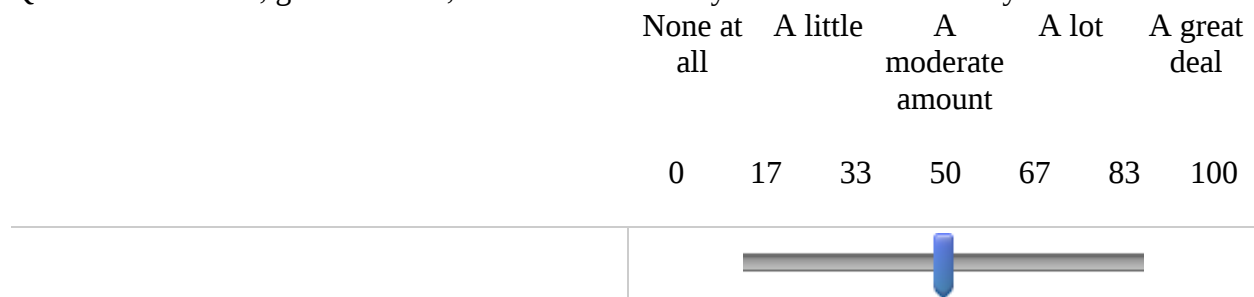
Q4.15 Thinking back, how comforting was the experience of receiving the child's autism diagnosis during the feedback?



Q4.16 To what extent has the feedback met your needs?



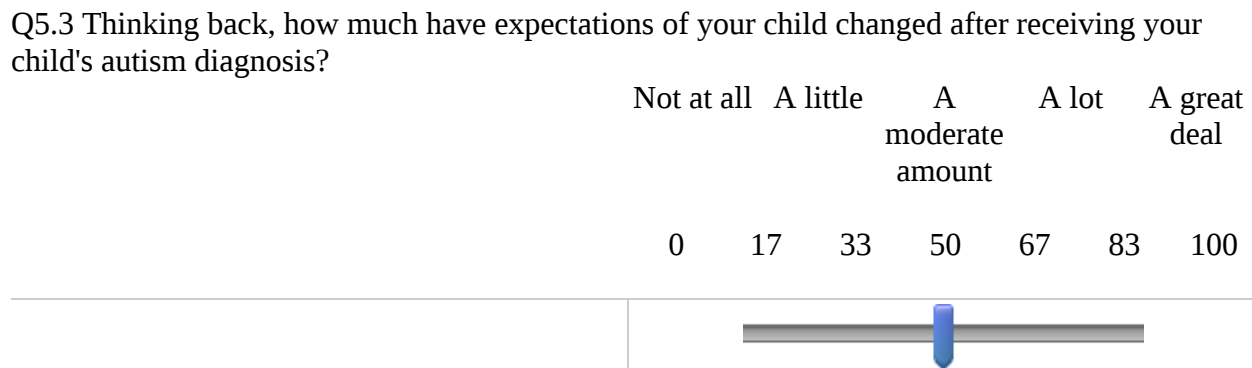
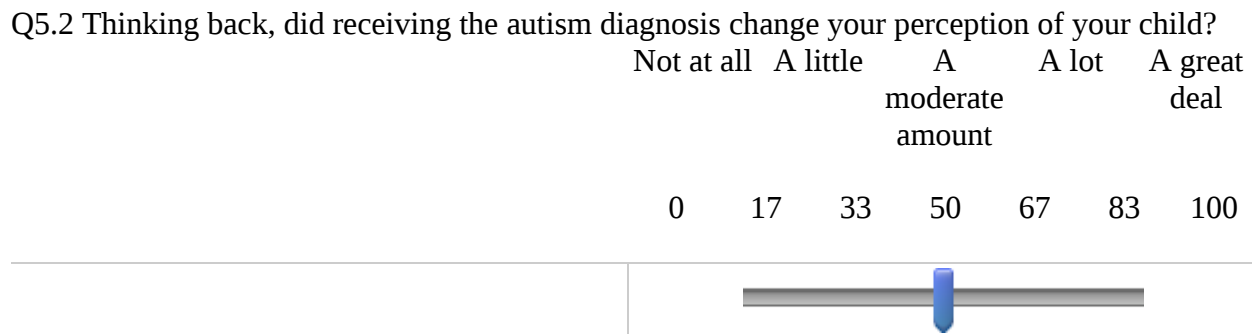
Q4.17 In an overall, general sense, how satisfied were you with the feedback you received?



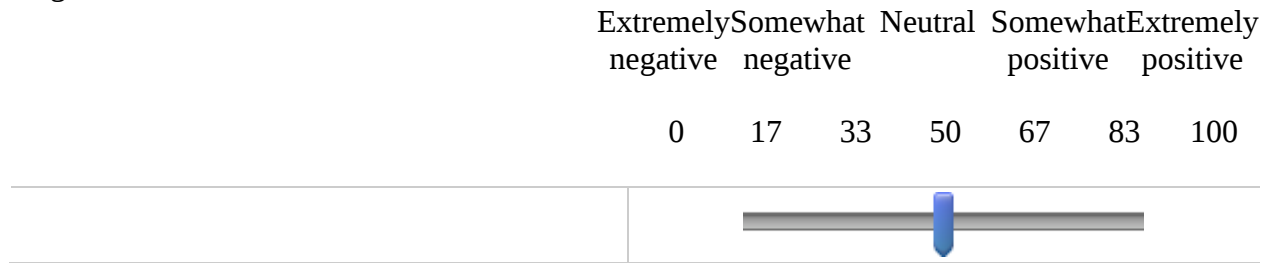
Q4.19 Was there something that hindered your ability to follow through with the provided recommendations? (select all that apply)

- ☐ Lack of finances
- ☐ Lack of time
- ☐ Recommended services (e.g., therapy) were not available at my location
- ☐ Recommended services (e.g., therapy) were not available in preferred language
- ☐ Lack of knowledge/familiarity with the recommended services
- ☐ Fear/shame
- ☐ Nothing prevented me from following through with the provided recommendations
- ☐ Other: _____

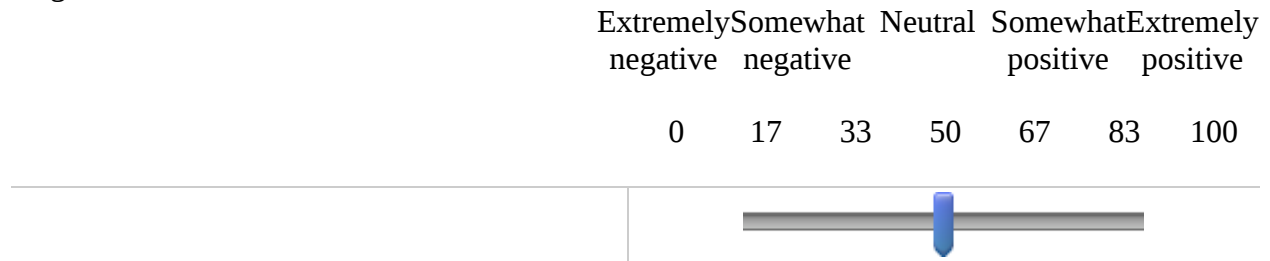
Q5.1 Lastly, we would like to ask about some of your experiences after the autism evaluation.



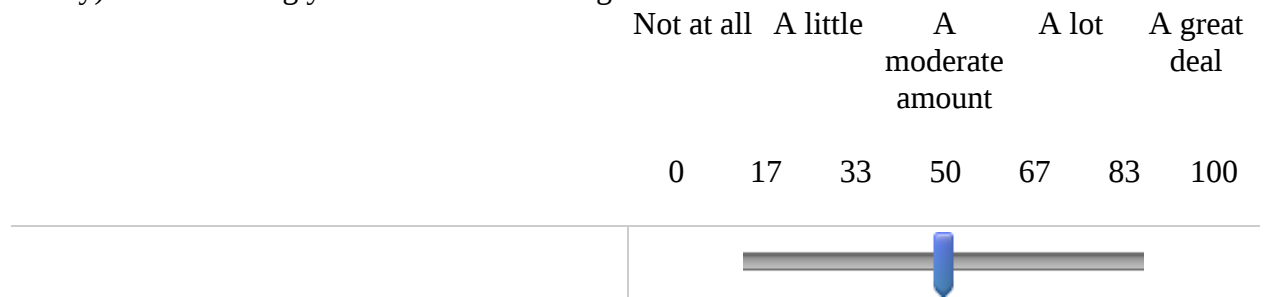
Q5.5 In general, how was your family's immediate response to the news that your child was diagnosed with autism?



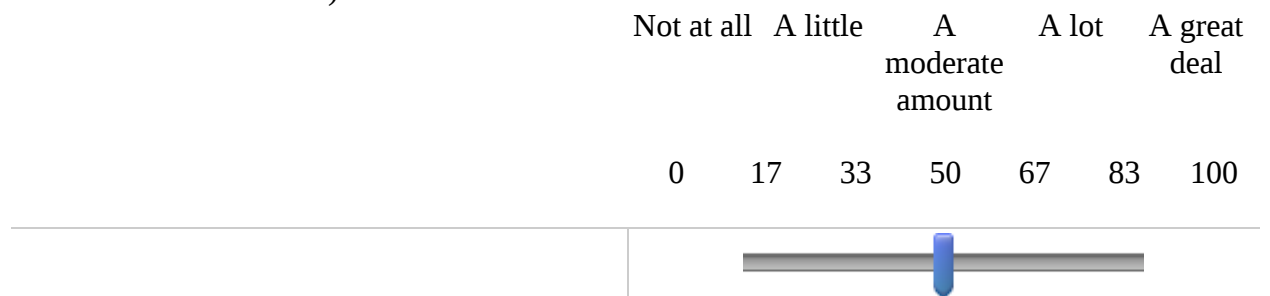
Q5.6 In general, how was your friends' immediate response to the news that your child was diagnosed with autism?



Q5.7 Thinking back, how supportive was your community as a whole (including friends and family) after receiving your child's autism diagnosis?



Q5.8 Thinking back, how socially stigmatizing was receiving your child's autism diagnosis? (Social stigma can include prejudice, discrimination, and negative attitudes against persons with autism and their families)



Q5.9 Do you have any additional information about your experience with the autism evaluation process (including pre-evaluation, testing, feedback, and post-evaluation) that you would like to share with us?

Q6.1

Thank you for your completing our survey! We appreciate your time and insight. To enter the raffle for one of the \$50 Amazon gift cards, please click on the link below. The link will redirect you to a different website where you will be prompted to type your email address. Doing so allows us to keep your identity anonymous by not directly associating your email address with your responses on this survey.

For more resources about autism, feel free to visit the following websites:

<https://nationalautismassociation.org>

<https://autisticadvocacy.org>

<https://www.autism-society.org>

<https://www.autismspeaks.org>